

ABSTRACT

Cherry Maynor Beasley. LUMBEE WOMEN BREAST CANCER SURVIVORS
STORIES: UNDERSTANDING THE EXPERIENCE

(Under the direction of Dr. Martha R. Alligood) College of Nursing, December, 2009.

The purpose of this interpretive study was to understand the experiences of Lumbee women breast cancer survivors from the text of their oral stories about their life events related to surviving breast cancer. Lumbees, the largest American Indian tribe east of the Mississippi and the largest tribe never to have been confined to a reservation, are a unique people and are yet to be addressed in the nursing literature. As an oral people, Lumbees use their stories to recall past struggles and to instruct others who are encountering difficulties. Their stories revealed the meaning for them of surviving breast cancer as well as the foundations for their health care decisions. The research method delineated by Alligood and Fawcett within Gadamerian philosophical hermeneutics was used in this study because it allowed the researcher, a Lumbee nurse, to interpret the stories, leading to an understanding of these women's experiences. As a result of this study, the interpreter's understanding of breast cancer survival of Lumbee women changed to now include: a) the reciprocity of the experiences in the personal and communal worlds, b) the phases of change are a critical part of survival, c) the realization that the personal and communal worlds undergo the same three phases but have different patterns that are used to assist in survival, and d) survival is a transformative process for the woman and her community.

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LUMBEE WOMEN BREAST CANCER SURVIVORS' STORIES:
UNDERSTANDING THE EXPERIENCE

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DEDICATION

This dissertation is dedicated to the Lumbee people who, through the fusions of horizons, have survived many changes and are continuously being transformed.

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First and foremost, I am thankful for the women who shared their stories with the hopes that they would benefit others. As they have shared their stories to benefit others, may this dissertation serve as my voice, which joins theirs to aid Lumbees, breast cancer survivors and those who care for them. From their stories I have gained the courage and energy to complete this work.

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Figure 1

Model of Findings

CHAPTER 1: PROBLEM FORMATION

Through their stories, Lumbee women breast cancer survivors reveal the meaning and the reality of the experience for themselves. These experiences provide the bases for ideas or beliefs through which they interpret and interact with the world to bring about change. Experience for these survivors can only be fully understood within meaningful context, linking their philosophical, environmental, cultural and psychological consciousness and unconsciousness. Benner (1999) observes that teleological explanations and understanding require inclusions of meaning and self-interpretation in the study of health, illness and suffering which are ultimately expressed through language. People who share their stories share the wisdom they obtain from their experiences and offer it for others to use in their own journeys, but the key to unlocking such wisdom is listening to and reflecting on the stories one hears within one's own world. As health professionals, nurses acknowledge the interconnection among meaning, understanding and interpretation in the health-illness experience as they listen to others' stories and connect with them to better understand the described experiences. This allows the nurse and patient to co-create their lives and world.

Stories reveal both the common and unique themes that guide individuals when confronted with health challenges, themes that serve as reminders that the whole is created by melding differences, each offering one's own wisdom to the greater story. Nurses gather these themes, both common and unique, and use them to develop their own wisdom as healers then offer it to those patients they subsequently encounter in their own journeys. According to Struthers and Littlejohn (1999) awareness of the rhythmicity of life allows nurses to inform, transform and perform healing by responding to the map inside themselves.

This research study is designed to understand the experiences of Lumbee women breast cancer survivors from their oral accounts which have been taped and transcribed. Working from her context as a Lumbee nurse, the researcher interpreted the texts to determine common and unique themes among these women, leading to better understanding of their experiences and

ultimately, to a better understanding of American Indian life ways and better care from the nurses who serve this population of cancer survivors.

Justification for Studying the Phenomenon of Interest

Since Lumbee women breast cancer survivors are the focus of this study, this section provides a brief history of the Lumbee Indians and examines the current health research literature about them. The section will conclude with a brief overview of the use of nursing models to understand the American Indian population.

The Lumbees

The Lumbee people: Historical and cultural context. According to the United States Census in 2006, an estimated 4.4 million Americans declare a racial heritage of either American Indian or Alaskan Native alone or in combination with another racial origin. These American Indians or Alaskan Natives descend from more than 600 tribal groups (U.S. Census, 2006). The Indian Health Service provides care for approximately one-third of these persons, primarily those who live on or near federal reservations (Indian Health Service, 2007).

The Lumbee people are a group of American Indians who live primarily in the southeastern United States and include more than 50,000 enrolled tribal members (Lumbee Tribe, 2002). The Lumbee tribe is the largest east of the Mississippi River and the largest tribe without an established reservation. The Lumbee people have never been wards of the federal government nor have they received services from the Indian Health Services. The federal government recognizes the Lumbee as an American Indian people as evidenced by their status in census data beginning with the 1790 census and by federal documents that describe the relationship between the Lumbee people and the federal government (Dial, 1993). Lumbees cling fiercely to their homeland along the eastern coast of the United States with the majority of tribal members living in modern day Robeson, Hoke and Scotland counties. Robeson County has been historically and still remains the center of tribal activities (Lumbee Tribe, 2007).

Like many eastern tribes that had early contact with European settlers, the Lumbee people have a stormy history of being betrayed, separated and forgotten (Dial & Eliadies, 1975;

Maynor, 2005; Locklear, 2005; Crenshaw, 2005). Yet by most standards, the Lumbee are a successful people who are defined by their complex kinship patterns and attachment to place, their homeland in southeastern North Carolina. After surviving the government's numerous attempts to move American Indians westward, Lumbees struggled through segregation in the South. Being denied the opportunity to participate in either White or Black institutions, the Lumbees formed their own school systems, civic institutions, and businesses. In 1887 they established the first four-year educational institution for American Indians in the nation, The Croatan Normal School, which evolved into what is now the University of North Carolina at Pembroke (UNCP). The Lumbee Bank, the first bank chartered by American Indians in the nation, is yet another example of the continuing accomplishments of the Lumbee.

Lumbee health challenges. Nationally and in North Carolina, American Indians experience significantly higher disease burdens and health disparities. The Indian Health Service (IHS) attributes the shorter life expectancy and disproportionate disease burden suffered by American Indians to low educational attainment, high levels of poverty, poor access to health services and cultural differences (IHS, 2007). Others note the role of historical trauma and cultural differences as primary contributors to the health disparities among American Indians (Struthers & Lowe, 2003).

Because of the lack of information about the state's American Indian populations, the North Carolina State Center for Health Statistics (SCHS) completed a study of the risk factors and conditions among the adult American Indian population (Gizlice & Huston, 2004). This study revealed that North Carolina's American Indian population have a significantly higher rate of chronic diseases, higher participation in risky behavior, less access to services and a lower quality of life than the state's white population. Such was true for 17 of the 20 factors included in the study (Gizlice & Huston, 2004). The North Carolina Office of Minority Health and Health Disparities (NCOMHHD) and State Center for Health Statistics (SCHS) issued two monographs detailing the health disparities experienced by the state's minority populations. Using the state's white population as basis for comparison, the monographs clearly show the level of health

disparity among the various populations in North Carolina. The second monograph, released in 2006, reports that compared to the state's white population, American Indians are (a) 2.6 times more likely to live in poverty, (b) 1.7 times more likely to have no health insurance, (c) 2.2 times more likely not to have visited a physician in the past twelve months due to cost, and (d) 1.3 times more likely to be in poor health (NCOMHHD & SCHS, 2006). All in all, North Carolina's American Indians suffer more from the burden of chronic disease, have a higher number of risk factors, experience higher levels of poverty, and are more likely to lack access to health care services than all other ethnic groups in North Carolina. These findings are especially significant since more than 50% of the state's Indian population is Lumbee who reside in Robeson County, the site of this study (North Carolina Commission of Indian Affairs, 2007).

Health research about the Lumbee people. Because of the Lumbee nation's size, concentration of location, and complex social history, researchers from the humanities and social sciences have often studied the Lumbee people. More than 70 articles and dissertations about Lumbees have been written, most centering on the Lumbee struggle to survive as a separate people, their pursuit of education, their complex social structure and unique language patterns. In addition to the two government reports previously cited, a comprehensive literature review revealed 15 dissertations and research articles about American Indians' health and health patterns that focused on or included the Lumbee (Arcury et al., 2006; Baker, Cross, Greaver, Wei & Lewis, 2005; Bell, 1993; Bell et al., 2005; Beltrame, 1976; Center for Disease Control, 1991; Farmer, Bell & Stark, 2005; Hudson, Armachain, Beasley & Carlson, 1998; Knick, 1986; Levin, Welsh, Bell, & Casper, 2002; Locklear, 1985; Michielutte, Dignan, Sharp, Blinson, & Wells, 1999; Spangler & Bell, 1997; West, 2004; White, 1982).

One group of researchers authored five of the articles from three studies that focused on cervical cancer screening, diabetes and behavioral risk factors in North Carolina including Lumbees (Arcury et al., 2006, Bell et al., 2005; Farmer, Bell & Stark, 2005; Levin, Welsh, Bell, & Casper, 2002; Michielutte, et al., 1999). In these articles, the researchers detail Lumbee women's extensive use of tobacco products (Farmer, et al., 2005), limited physical activity (Arcury et al.,

2006), high levels of depression in the chronic disease experience (Bell et al., 2005), positive attitude towards cervical screenings (Michielutte, et al., 1999) and numerous cardiovascular risk factors (Levin, Welsh, Bell, & Casper, 2002). Michielutte et al. (1999) report a positive correlation between community association and positive attitudes towards screening. The other health studies that include Lumbees provide a profile that Lumbees honor their elders and have a low tolerance of elder abuse (Hudson, et al., 1998). They experience a higher occurrence of otitis media (Knick, 1986), higher incidences of postpartum depression (Baker, et al., 2005), higher incidence of social stress (Locklear, 1985; West, 2004), high rates of alcoholism (Beltrame, 1976; White, 1982), and higher prevalence of cardiovascular diseases and cardiac risk factors (Bell, 1993; CDC, 1991; Spangler & Bell, 1997) compared to the national and state populations.

Breast cancer in Lumbee women. A review of national and state studies reveals limited accurate information about the burden of breast cancer in American Indian women and a scarcity of information in the nursing literature. National studies indicate that American Indian women may have a lower incidence rate of breast cancer than white women in the United States, but that they have a higher mortality rate (National Cancer Institute [NCI], 2007). Most of the studies that include American Indian women used Surveillance and Epidemiological and End Results (SEER) data that have been found to underestimate the incidence and mortality rates in American Indian women who reside outside Arizona and New Mexico (Burhansstipanor & Digner, 2000). Several studies indicate that the age-adjusted incidence rate for breast cancer among American Indian women in North Carolina is at least as high as among other women in North Carolina (NCOMHH, 2006; Yankasas, 2005). In an unpublished study conducted by the North Carolina Cancer Registry, the rates of breast cancer in American Indian women in North Carolina appeared to approach the same levels of breast cancer in African American women (Personal communication, Yankasas, 2007). Farmer, Bell and Stark (2005) conducted an exploratory study of the cancer screening predictors and practices of Lumbees, reporting that Lumbees were more likely to have been screened once for breast, colon or prostate cancer than the national average. Predictive factors for participation in cancer screening behaviors include youth, educational level, and health

status. These data, part of the Lumbee Diabetes and Health Study, were collected by telephone survey that asked, "Have you ever been checked for breast cancer?" (Bell et al., 2005; Farmer, et al., 2005). Since interviews did not follow up on positive responses, the study did not provide a complete picture of the patterns of participation in screening behaviors.

Two significant deficits were noted that are important and support the need for this study. No studies were found that focused on the experience of Lumbee men or women with cancer, nor any that provided information about Lumbee cancer survivors. And especially important, no nursing studies about the Lumbee people were found. Therefore, this study addresses this lack of knowledge about cancer survivorship in this population and begins to develop nursing knowledge about the experiences of cancer survivors in the Lumbee population.

Understanding the experiences of Lumbees through oral accounts. Oral tradition, particularly storytelling, has formed and shaped the identity of the Lumbee tribe. Recent social research about Lumbee Indians identifies the severity and extent of human suffering as an important aspect of Lumbee culture (Crenshaw, 2005; Locklear, 2005; Maynor, 2005). The suffering is expressed in a variety of related social problems such as poor health outcomes, poverty, lack of education and un- or underemployment. Crenshaw (2005) argues that Lumbees place much emphasis on the power of prayer to heal and to relieve suffering. He identified a distinct communal behavior that he termed "communal vocalization," a practice described as using individual stories, yet sometimes spoken simultaneously, to support the primary speaker. Locklear (2005) recounted a similar communal voice among the Cherokee who sang to support sufferers on the Trail of Tears. Maynor, in a 2003 documentary film, depicted the Lumbee use of singing for support and to strengthen family and community bonds. No studies were found that examined these oral coping strategies used by the Lumbee people when they are confronted with health problems and sufferings.

Researchers in the disciplines of education, history and the social sciences have used qualitative methods to study the Lumbee people. Several cited the importance of oral accounts and/or stories to understand the Lumbee, but only one study that used a qualitative approach is

found in the health science literature (Michielutte, et al., 1999). The single qualitative health study, a follow-up from the cervical cancer study noted above, purposed to understand why Lumbee women responded differently to a specific intervention that had been included in the original study design. Though the follow-up study was limited in purpose, the authors reported a positive association between the woman's participation in the intervention and their community and family involvement. However, these researchers did not address the coping strategies of Lumbee people nor did they include oral accounts or stories in the study methodology. Therefore, this study was designed to address this deficit and contribute to understanding the Lumbee experience through interpreting rich oral accounts of Lumbee women breast cancer survivors. Identifying themes they use for coping with the experience of surviving breast cancer and gaining understanding of them as breast cancer survivors has contributed to a base of knowledge needed by nurses and other health care professionals to provide culturally appropriate care.

Summary of the Justification for Studying the Phenomenon

Lumbees, the largest American Indian tribe east of the Mississippi and the largest tribe never to have been confined to a reservation, are a unique people who have been studied by researchers in the disciplines of education, the humanities and social science. Yet there are no studies in the current nursing literature about these people. While current data indicate that Lumbees have as great a disease burden from breast cancer as other North Carolinians, there are no studies about their experiences as cancer survivors in general or breast cancer survivors specifically. As an oral people, Lumbees use their stories to recall past struggles and to instruct others who are encountering difficulties. However, there are no qualitative studies of their stories that reveal their experiences with common health challenges in general or breast cancer specifically. This study contributes to the body of knowledge about the Lumbee by using their stories to understand their experiences as breast cancer survivors and to begin to understand the nursing needs of the Lumbee.

Statement of Purpose

The goal of this study is to interpret the historical experiences of Lumbee women breast cancer survivors from the text of the stories they have shared.

Research Question

What do Lumbee women tell about their experiences of surviving breast cancer?

Assumptions, Definition and Limitations

Assumptions

1. Stories of Lumbee women breast cancer survivors can be interpreted to reveal understanding of their experiences.
2. The text of the oral accounts of the experiences of Lumbee women breast cancer survivors will reveal their illness experience.

Definitions

Lumbee woman. In this study, a woman is a Lumbee if she identifies herself as Lumbee and has maintained contact with tribal members who live in the Lumbee homeland in Hoke, Robeson and Scotland counties of North Carolina. The definition complies with the United States Census definition of race and the Lumbee Tribe's definition of eligibility of tribal membership as any person who has a direct natural descent of someone listed in a primary source document and who maintains contact with the tribe (Lumbee Tribal Ordinance, 2002).

Breast cancer survivor. In this study any Lumbee woman who has been diagnosed with breast cancer that has been confirmed with a positive biopsy. Women with various types and stages of breast cancer are included. The definition is congruent with the definitions used by National Coalition for Cancer Survivorship (2006) and the National Cancer Institute Office of Cancer Survivorship (2006).

Experience. Experience is the lasting meaning that surviving breast cancer has for the survivor and belongs to the unity of the person. Through experience one attains a new mode of being; experience is ontological (Gadamer, 1975).

Stories. Stories are defined as the oral narratives of the historical accounts of Lumbee women who agreed to be interviewed and have their oral accounts of their experiences of breast cancer recorded. These stories are oral narratives of their experiences as breast cancer survivors and are constructed based on their understanding of the experience at the time of the interview.

Understanding. In this study understanding is a conscious, productive process realized only by fusing horizons through the dialectic questioning and answering between the text and the interpreter (Gadamer, 1975). The purpose of understanding is to gain insights and acknowledge truths. Since understanding is realized through a fusion of horizons, one must recognize that (a) a horizon is a range of meanings extending to include more than one element and (b) that there is more than one interpretation of the text because both horizons construct the range of meaning (Gadamer, 1960/1975; Hekman, 1986).

Delimitations and Limitations

Delimitations. This study is confined to the stories of Lumbee women with breast cancer who were interviewed from 2002 through 2004 by interviewers employed by the Breast Cancer Registry. All the interviews occurred in southeastern North Carolina at the place selected by the Lumbee woman. The interviews have been recorded and transcribed verbatim. The taped interviews and verbatim transcripts were available for this interpretive study.

Limitations. In interpretive studies, the findings are subject to other interpretations.

Justification for Research Method

Gadamerian philosophical hermeneutics and American Indian culture are ontologically and methodologically congruent. In American Indian theology, humans co-create with entities in the universe and such creation is an on-going process. Even though each American Indian tribe has its own beliefs, history, traditions and values, many common themes and similarities exist. One aspect of most American Indian cultures is the use of oral stories to pass information from one person to the next and from one generation to the next. The use of oral accounts, especially stories, is a foundational component of Lumbee culture. Deese (2003) describes the worldview of the Lumbee as defined by place and relationships. In her dissertation, she relates stories of

Lumbees describing their attachment to the land, family and community. Maynor (2005) related how the people changed to maintain their kinship system and connection to the land. Again, using stories and oral accounts, she argues that the Lumbee people changed in mutual rhythmical interchange with their environment that allowed them to survive as a people. Bleu (2005), writing in the *Lumbee Problem*, details the mystery of the Lumbee who, despite all anthropological odds, have survived. She notes the intense sense of community, the use of language and the attachment to place as explanations of the Lumbee's success. Therefore, as these studies indicate, the Lumbee people use oral accounts to assure continual community survival and to thrive as individuals and community in a constantly changing world.

Nursing's simultaneous action worldview is congruent with the American Indian philosophical foundation. In the simultaneous action worldview, the human in the nursing metaparadigm is defined as a "unitary human, who is regarded as a holistic, self-organized field" (Fawcett, 2000, p. 12). In this worldview the human is both more than and different from the sum of parts. Discussing her conceptual framework, Martha Rogers (1994) viewed the reality of synthesis and holism as new. However, this has been the worldview of the American Indian, including Lumbees, for ages. In the *Wisdomkeepers: Meeting with Native American Spiritual Elders* (1990), a collection of oral accounts from different tribal leaders including Lumbee, White Deer of Autumn reveals this worldview.

Reading the words of the Wisdomkeepers, we must understand that these terms - God, Creator, and Great Spirit - have been used to convey the concepts that all things are interrelated and equal part of the whole; that we are like a drop of rain which will one day return to the ocean, that we are like candles lit by the fire of the sun, forever part of it. The Wisdomkeepers all share the idea that the four-legged and winged nations, the creeping and crawling ones, the plant and tree nations, and those who dwell among the stars, are descended from and are a part of this Great Holy Mystery (Wall & Arden, 1990, p. 5) .

The stories that Lumbee women breast cancer survivors tell about their experiences are not separate from themselves but reveal who they are, their pattern within. Nurses as listeners are called to co-create with them an understanding of the experience that can inform, transform and perform healing by responding to the map inside themselves.

The goal of this study is to gain an understanding of the experience of Lumbee women breast cancer survivors using a constructive ontology and epistemology since the emphasis is on understanding. Interpretive hermeneutics emphasizes understanding and context of shared things, and practices and histories to make sense of the world (Fleming, Gaidys & Robb, 2003; Gadamer, 1999). Benner relates this to nursing science and the understanding of a person's action in the health-illness experience. She notes, "...human experience is based on participating in linguistic and cultural practices that are not reducible to context-free elements" (Benner, 1999, p. 304). She proposes that "...hermeneutics is used to understand everyday practices, meanings and knowledge embedded in skills, stress and coping" (p. 306). Therefore, using Gadamerian interpretive hermeneutics, one can gain an understanding of Lumbee women's experience as breast cancer survivors through interacting with the text produced from their oral accounts which provide insight into their context and understanding.

Significance

Nursing, as a human science, is tasked with interpretation and understanding. When nurses approach patients' stories, they do so to better understand two complex scenes: where the health-illness experience enters the patient's world and where the patient enters the world of health care or the nurse's world (MacIntyre, 2001). This study is significant to nursing because it contributes to nurses' understanding of the Lumbee people, to the experience of surviving breast cancer of American Indian women, and specifically to Lumbee women who are breast cancer survivors.

Nurses can use this understanding to co-create with the Lumbee people and possible other marginalized people in society, giving voice and visibility to them in the majority society. In order to do so, nurses must understand not only others but themselves. In this study the

researcher is emic to the Lumbee people and to the profession. That is – the researcher is a Lumbee woman and a nurse, a unique position that provides a perceptual and intellectual merging of nursing and Lumbee cultures and histories, leading to a better understanding of nursing and oneself as a nurse. Such perspective will serve as a foundation for designing meaningful care for Lumbee people.

Summary

The purpose of this interpretive study was to understand the experiences of Lumbee women breast cancer survivors from the text of their oral stories about their life events related to surviving breast cancer. Their stories revealed the meaning for them of surviving breast cancer as well as the foundations for their health care decisions. Since nurses use their understanding of a person's health-illness experience to design nursing care, it is critical that nurses actively seek an understanding of the patient's experience. Gadamerian philosophical hermeneutics is the method used in this study because it allowed the researcher, a Lumbee nurse, to interpret the stories, leading to an understanding of these women's experiences. This study is significant to nursing because it will contribute to the nursing knowledge about the study population, a topic which has not yet been discussed in the nursing literature. Based on this understanding, nurses can better address the nursing needs of this population and design culturally appropriate nursing interventions and meaningful care.

CHAPTER 2: LITERATURE REVIEW

The goal of this study is to understand the experiences of Lumbee women breast cancer survivors from the context of the stories they share. In this chapter the reader will find a review of relevant literature that focuses on three main topics: (a) understanding the Lumbee people, (b) understanding the experiences of American Indian women who are breast cancer survivors, and (c) understanding the experiences of American Indians through nursing frameworks. Of particular importance in this review is the limited health research about the Lumbee and the lack of

research on their experiences with health and excessive disease burden. Since research was not found about Lumbees in the nursing literature, the limited literature about breast cancer and the experiences of American Indian women breast cancer survivors will be reviewed. Finally, the literature about the purpose and development of the Conceptual Framework of Nursing in Native American Culture (CFNNAC), which has been proposed by Native American nurses to provide a framework for nurses who are interested in American Indian people, will be reviewed.

Understanding the Lumbee People

A central purpose of this research is to understand the experiences of Lumbee women breast cancer survivors. In order to understand one must realize that events and experiences are significant and that the worldview of the people is essential to the culture (Dodgson & Struthers, 2005; Phillips, 2007). Hence, one must first be aware of the historical context, the socio-cultural background, and the collective experiences of the Lumbee. Historical and socio-cultural information that provides the context of Lumbees is available in books and dissertations. However, there is limited health research available. That which is available is discussed extensively here and includes studies published in refereed journals and dissertation research. Neither studies about experiences of breast cancer survivorship nor nursing studies on this population have been found.

Though a relatively small group, the Lumbee people have been frequently studied, probably because of their social and political history. Most of this research is presented in dissertations in the areas of education, the humanities and social sciences. Lumbees were included in the study population of thirty-two (32) dissertations, with Lumbees being the only population studied in 25 of these studies. These studies, both qualitative and quantitative, come from a wide range of disciplines: Education (12), Anthropology (5), American Indian Studies (4), Psychology (4), Sociology (2), Botany (1), History (1), Linguistics (1), Nutrition (1) and Political Science (1). In sixteen of these studies, the researcher is Lumbee.

Historical and socio-cultural context of the Lumbee

The Lumbee Indians have lived in Robeson and surrounding counties in southeastern North Carolina for hundreds of years. As with other people, aspects of their culture and community have changed over time. Historically, they have lived in relative isolation from other people but currently exist in multi-racial, culturally diverse, pluralistic communities while remaining primarily in southeastern North Carolina. Despite numerous economic and political hardships, Lumbees have maintained close connections to their homeland, strong family kinship patterns, and a sense of themselves as an Indian people.

Historians have constructed a history of the Lumbees that is characterized by complexities, questions and ambiguities. Archaeological evidence indicates an American Indian presence in the area for more than 14,000 years (Thomas, R., 1976). These people have claimed or been assigned different tribal names and political affiliations since their coalescence along the swamps and stream tributaries to the Lumber River in the 17th and 18th centuries. The noted Lumbee historian, Adolph Dial (1993), explains that this group of people has officially been known as the Croatan Indians of Robeson County (1885), the Indians of Robeson County (1911), the Cherokee Indians of Robeson County (1913) and finally, Lumbee (1953), a name selected by the people and adopted from the river on whose banks they make their homeland. The Lumbee people, whose oral histories describe them as a group originating from several different tribes and peoples, petitioned the governments of North Carolina and the United States for the right to name themselves and for self-determination. North Carolina granted the request in 1953, and in 1956, the United States Congress again acknowledged the Indian identity of the Lumbee tribe, but denied them the federal benefits or services normally granted to other tribes. Today, the Lumbees continue to pursue the federal benefits and services denied in the 1956 law (Lumbee, 2007).

The Lumbees are a people who have and continue to struggle to maintain their collective identity and be accepted as one. Although historians debate the origins of the current day Lumbee, they all acknowledge that the Lumbee people are part of the same extended kinship group and share a deep attachment to their homeland in Robeson County. Swanton (1946) and Evans (1995) describe the group of people known as the modern day Lumbee as a combination

of many tribal groups fleeing from war and disease to the protection of the swamps of the Lumber (also known as the Lumbee) River. The current day Lumbee tribe is composed of the remnants of Cheraw, Hatteras, Tuscarora, and related Siouan-speaking Indian people (Dial, 1993). Dial and Eliades (1975) confirm through Lumbee oral tradition that one of the groups who sought refuge with the natives along the banks of the Lumbee were the survivors of John White's "Lost Colony." These stories corroborate what European settlers, who first explored the Lumbee River in the 1730s, reported: "a large tribe of Indians, speaking English, tilling the soil, owning slaves and practicing many of the arts of civilized life" (Dial, 1993, p. 20). While tilling the soil and owning slaves were not unusual practices among eastern Indians, speaking English was. The "Lost Colony" theory is the most convincing explanation about how the Indians of Robeson County came to speak a different English dialect than the other inhabitants of Robeson and surrounding counties. Lumbee oral stories relate how the different "sects" came to live with the people, who and from where these different people came and why. The Lumbee kinship pattern often follows these diverse origins. However, until the name Lumbee was proposed and adopted in the 1950s, the internal name used by the people for themselves was "Our people" (Beltrame, 1976). This term is still heard frequently in intra-tribal communication. Understanding this complex history of a people who have endured grief and trauma, yet survived, and their accounts that have been passed down in oral and written records is critical to this study. Similar paths of historical trauma and retelling in oral accounts are found in the lives of other American Indian tribes. In this process, the grief and struggle become one's own and provide the context from which one views the world (Alvord & Van Pelt, 2000; Dodgson & Struthers, 2005).

Just as understanding the historical struggle of identity is critical to understanding Lumbees, one must also understand their connection to place. Geographically, the Lumbees live primarily in specific sections of Robeson, Hoke and Scotland counties. In these sections, the resident population is usually more than 90% Indian if not totally. When the researcher was growing up in Pembroke, the geographic and political center for the Lumbees, there was one

street where African Americans lived and one where White Americans lived. Now, even these are primarily inhabited by Lumbees.

Many Lumbees move to other geographic areas in search of employment, and they establish Lumbee communities in many of these areas. The role of place is critical to the Lumbee worldview and is maintained by Lumbees whose primary residences are outside the homeland (Deese, 2002; Crenshaw, 2005). There are Lumbee communities in urban areas in North Carolina as well as in Detroit, Michigan, and Baltimore, Maryland. Lumbees frequently migrate between other cities in the state and nation to Pembroke. Families who migrated generations ago still refer to Pembroke as home. The local Lumbee newspapers have stories of the people who live in the Lumbee diaspora. Most return home to be buried, and many return to give birth. Annually, Lumbees from around the country make a pilgrimage to Pembroke to celebrate their history and achievements, re-tell stories and participate in tribal activities. The understanding of the role of place and the close connection between Lumbees who live within the traditional homeland and those who live outside the traditional geographic community provides the socio-historical context for this study. The socio-cultural network of kinship and place are deeply ingrained in the Lumbee people such that only when considering them can one truly understand the experiences of Lumbee women who are breast cancer survivors.

In addition to geographic isolation, segregation forced the Lumbees into social isolation. Though this limited many opportunities, the Lumbees used it to maintain their intense group identity. Robeson County and other counties in the region maintained separate schools for American Indians. Lumbees still attend church in segregated congregations and maintain segregated religious organizations. For example, the Burnt Swamp Baptist Association is composed of all Indian Baptist congregations in North Carolina and has its headquarters in Pembroke. Lumbees provide much of the financial and leadership support needed for these organizations to continue.

Such social isolation is important to understanding the social context of Lumbee women with breast cancer. Because of age, many of the women interviewed in this study attended

schools that were predominately Lumbee, practiced religion in churches that are predominately Lumbee and lived in predominately Lumbee communities. This social isolation in combination with kinship and attachment to place serve to provide context for understanding experiences of the women in this study.

The historical struggles, attachment to place, and kinship have resulted in four cultural and social themes recurring in research on the Lumbee people: (a) biculturalism, (b) struggles of equality, (c) group identity, and (d) intense kinship patterns. Because of their history, geographical location and their political struggles, Lumbees' world blends two different worlds: that of the Lumbee and that of the majority culture (Chamberlain, 1980; Crenshaw, 2005; Deese, 2002; Locklear, 1985; Lucas, 2006). To Lumbees this blend of cultures is their world. The complex cultural heritage, often known as biculturalism, requires that the Lumbee know how to communicate and act in more than one cultural group, a phenomenon which is its own experience and which often contributes to the struggles of indigenous people (Dodgson & Struthers, 2005; Struthers, Lauderdale, Nichols, Tom-Orme & Strickland, 2005). Since experiences and meanings of health, illness, sickness and suffering have strong cultural ties, such context is important in this study (Lowe & Struthers, 2003; Purnell & Paulanka, 2003; Reed, 2003; and Spector, 2004).

In addition to being forced to live in a complex culturally structured world often with two different social norms, the Lumbees have had to struggle to maintain the group's identity in a black-white society. Dodgson and Struthers (2005) acknowledged that many indigenous people chose to adopt mainstream culture instead of being marginalized; however, the Lumbees have chosen to struggle against social and political forces to maintain a strong group identity (Baker, 1982; Dial, 2006; Maynor, 2005; Oxendine, 2004; Stein, 1999; Woods, 2001). Building on the theme of intense group identity, Bryant, a Lumbee researcher studying in education (1998), used the Helm's People of Color Racial Identity Attitude Scale (POCRIAS) to investigate the racial attitudes of Lumbee college students. He found that for many, college was the first time they had spent much time outside the Lumbee community, resulting in their primary difficulty in adjustment

to college. Such was true even for Lumbees who attended college at the University of North Carolina at Pembroke, the first historical American Indian college located in their hometown of Pembroke. Most of the Lumbees in this descriptive study had been educated in schools that were primarily Lumbee. The difficulty adjusting is especially interesting since some of the study participants commuted to college while continuing to live at home. Chavis (1986), also a Lumbee educational researcher, examined the perception of Lumbee teacher-student relationships in an Indian school versus a racially integrated school environment. Using a theoretical framework that emphasized personal process including the categories of awareness, acceptance, sharing and choosing, he found that Lumbees in Indian schools perceived more awareness, acceptance and freedom to choose than those in integrated educational environments. Such studies clearly show the intensity of group identity for the Lumbee people.

While several studies described the intense kinship patterns, Maynor (2005) most clearly describes how the Lumbees used the federal government's policies to maintain the sense of place and people, building on the kinship pattern even during the segregation era. According to Maynor (2005) the Lumbee identity is developed with a complex layering that allows for them to disagree within the tribe while they preserve common identity and their distinctiveness from their black and white neighbors.

By 1930, Robeson County Indians had been shaping their kin network in this place for over 150 years, and one's family and home settlement were the fundamental way to identify oneself as an Indian. To be a Hammonds from Saddletree, a Lowry from Pembroke, a Brooks from White Hill, or an Oxendine from Union Chapel meant something to other Indians. It was their way of identifying another Indian's family and thus his likely reputation, economic background, political influence, and overall social "place" in the larger community. Locale thus reinforced family relations and cultural values and shaped the social cooperation and conflict that occurred within the Indian community (p. xx).

Still holding true today, when one Lumbee is introduced to another Lumbee, the first question asked is, "Who's your people?" (One of the featured tee-shirt designs at the 2008 Lumbee Homecoming asked this question.) In response one goes back at least two or three generations. It is not unusual to be questioned in detail about a great aunt or third cousin once removed. Often, a follow up will be "Where were you raised?" inquiring in what part of the Lumbee community you were born and lived as a child. For the Lumbee, these are critical questions to place one in social and cultural context.

Lumbee kinship ties and their connection to place are strong and continue to be quintessential in the heart of the people. Crenshaw (2005) compared the Lumbees with the Jews in terms of group cohesiveness, suffering, oral traditions, and value of the land. Dannenberg (1999) addressed this concept within the context of linguistics. She noted that while the Lumbees speak only English, they speak a different form than the other racial groups in Robeson County. A person with a trained ear can not only identify an individual as Lumbee based on the Lumbee dialect, but also can very often identify where in the Lumbee community the speaker originated.

The Lumbee's close yet complex kinship patterns support their strong group and individual identity as a people. Families include not only extended family members but also persons who are non-blood relatives. Many families live close together, with grandparents, aunts, uncles and parents sharing responsibility for all the children in the extended family. Ransom (1989) in *The tie that binds: The grandparent/grandchild relationship among the Lumbee Indians of Robeson County, North Carolina* noted that the grandparent/grandchild relationship is critical in the development of the Lumbee child to live as a productive citizen within the tribe. She found four values used by Lumbee grandparents: (a) awareness of the child, (b) acceptance of the child, (c) sharing of oneself as defined by time and energy, and (d) freedom of personal choice. Deese found these same concepts and values in her study in the area of educational counseling (2002).

Not surprising, the research themes of biculturalism, struggles for equality and intense group identity and kinship are apparent in research of Lumbee families who lived outside the

Lumbee traditional geographic community. Research studies of Lumbees who live in an established Lumbee community in Baltimore, Maryland, reflect these themes. Lumbee women (Globenshy, 1999; Makofsky, 1971; and Sui, 1998) and Lumbee youths (White, 1982) reported living in two different worlds (biculturalism), struggles of equality, and intense kinship and group identity. In these studies of Lumbees who live distant from the traditional geographic homeland, the study subjects reported the importance of place and people to them. In the three studies of women and the one study of Lumbee youth, Robeson County is the place called “home,” and Lumbees are “their people.” These studies reinforced the importance of these critical cultural themes because these Lumbees created a separate place for themselves which facilitated connections with other Lumbees, even in a “foreign land.”

Whether in Robeson County or other Lumbee communities, the socio-cultural context of place and kinship has been maintained at great cost to the Lumbee people. There have been stressful, open confrontations with other groups who live in close proximity to the Lumbees; Lumbee leaders have been assassinated and the Lumbees have a reputation as a violent and lawless people. For example, in 1958 Lumbees achieved national acclaim in a confrontation with the Ku Klux Klan, known still as the Battle of Hays Pond (Anonymous, 1958, Jan. 17).

No context of the Lumbee is complete without an understanding of the area in which they live and their demographics. Lumbees live primarily in Robeson County, an area that is racially, ethnically, and culturally diverse where three of the cultural groups (whites, blacks, and Indians) have traditional family ties to the land. Another cultural group, the Latino or Hispanic population, is moving to the area and calling Robeson County home. Overall, the county experienced more than a 17 % growth rate over the last decade (North Carolina State Office of Budget and Management, 2006). The county population as a whole is very poor. The estimated per capita income for Robeson County is only 59% per cent of the national average. Robeson County has a poverty rate of 32% in 2005 compared to 15% for N.C. and 13.3 % for U.S. (NCSOBM, 2006).

As a result of such poverty found in Robeson County, Lumbees experience social disparities that contribute to poor health outcomes and influence the context for health dilemmas.

The Lumbee experience poverty greater than 1.75% the state average (OMHHD & SCHS, 2006); one out of every four Lumbees drops out of high school compared to 1 out of 20 other North Carolinians, and 1 out of 6 for American Indians nationally (N C Division of Social Service, 2006) in addition to suffering excessive disease burden and limited access to health care (ONHHD & SCHS, 2006).

The historical and socio-cultural backgrounds of the Lumbees serve to inform this study by providing the required context for understanding their experiences and the meaning of these experiences to the subjects. In this study the Lumbees are understood as a people of mixed origins who have an intense attachment to kin and place. They have survived numerous hardships but remain a resilient people who maintain their tribal identity while learning to participate in the broader American society. This context of resilience, history, cultural milieu, and deprivation influences their health-illness experiences, a context essential to understanding the experiences of the Lumbee women breast cancer survivors in this study.

Health Research and the Lumbee:

One can more fully understand the Lumbee women's view of health-illness experiences by knowing the context of the general health status of the Lumbee population. Health statistics specifically about Lumbees are limited, but they can most often be extrapolated from statistics about North Carolina's Indian population, of which more than 50% are Lumbee, and Robeson County's health statistics, of which Lumbees comprise more than 38% of the total county population and more than 60% of the county's minority population (U. S. Census, 2003). (Often biostatistics is reported as white and minority; still these state and county statistics are useful for understanding Lumbee health in specific areas of the state such as in Robeson County.)

The rich cultural diversity of North Carolina is compromised by myriad challenges to good health. American Indians experience a high poverty rate, attain low educational achievement, indulge in risky behavior, face numerous environmental hazards, and have insufficient access to adequate health care. Both nationally and in North Carolina many health status outcome

measures are worse for American Indian populations. The contributing role of cultural diversity and ethnocentric forces to health outcomes is an ongoing debate in the health and social science literature.

As with social variables that influence quality of life, Robeson County lags behind the country and state in several key health indicators, such as infant mortality, life expectancy, heart disease, cancer, stroke, diabetes, and incidence of obesity. Two health indicators are traditionally used to compare the general health of populations: infant mortality rate and life expectancy. The infant mortality rate for the total population of Robeson County is 11.1 per 1,000 live births compared to 8.4 for the state. County specific life expectancy rates were not available (NCSCHS, 2006). However, a recent report based on mortality and North Carolina Behavioral Risk Factor Surveillance System (BRFSS) survey data indicates that while the life expectancy at birth for North Carolina's white population is 76.8 years, the life expectancy for minorities is 72.1 years. (NCSCHS, 2004) Residents of Robeson County experienced higher mortality rates than state residents in several indices: accidents and injuries (10.7 compared to 6.4), heart disease (332.2 compared to 243.2), cancer (222.7 compared to 199.7) and cerebrovascular accidents (94.0 compared to 70.7). Data in some areas such as mental health and environmental health are unavailable (Gizlice & Huston, 2004).

A close examination of the health indices for North Carolina's American Indian population reveals an equally dismal picture. The 2004 Behavioral Risk Factor Surveillance System (BRFSS) study used purposeful sampling to insure inclusions of American Indians (Gizlice and Huston, 2004). They conclude that North Carolina's American Indian population suffers from significantly higher rates of chronic diseases, higher risk factors, less access to services and a lower quality of life than the state's white population. These differences were true for 17 of the 20 factors included in the study (Gizlice and Huston, 2004). In the *Racial and Ethnic Health Disparities in North Carolina: 2006*, the North Carolina Office of Minority Health and Health Disparities (NCOMHHD) reports that compared to the state's white population North Carolina's American Indians are 2.6 times more likely to live in poverty, 1.7 times more likely to have no health

insurance, 2.2 times more likely not to have visited a physician in the past twelve months due to cost, and 1.3 times more likely to be in poor health (NCOMHHD & SCHS, 2006). Therefore, North Carolina's American Indians suffer more from the burden of chronic disease, have higher number of risk factors and experience higher levels of poverty and lack access to health care services. For this study, these findings are especially significant since more than 50% of the state's Indian population is Lumbee who reside in Robeson County (North Carolina Commission of Indian Affairs, 2007). In summary, Lumbees live in a county that is poorer and has poorer health outcomes than most of the state.

Published research on the health status, health patterns and practices of Lumbees is limited. The researcher could not locate any health research on understanding the experiences of Lumbees who have a health-illness experience; it is non-existent. Currently available literature reflects these findings: Lumbee women engage in numerous risky behaviors; they are concerned with the limited emic health care providers; the cost of health care is prohibitive; and the family and community have substantial roles in providing support and care. The entire body of health research about Lumbees has been reviewed to provide this study with a complete context of the health, disease burden and health care patterns of the Lumbees. This information in conjunction with the historical, social and cultural context presented above provides the contextual background for this study.

As revealed in the previous discussion of research studies that help to provide the historical, socio-cultural context for understanding the Lumbees, the themes of kinship, group identity, and biculturalism appear again in the health literature especially in the fields of psychology and mental health. Two of these studies focused on alcoholism in the Lumbee population. Beltrame (1976) studied drinking patterns in two different Lumbee communities, one within the traditional homeland and one outside the homeland. He concludes that alcohol abuse is higher in these communities than in the general population and attributes this situation to the economic, political and social struggles of the Lumbees. He provides examples of the struggle of living in two worlds. White (1982) used an experimental design to study Lumbee youths in

Baltimore, a community that had wide acceptance of alcohol abuse and reported high rates of alcoholism. He found that interventions that increased knowledge and self-worth decreased the acceptance of alcohol abuse in these youth. Locklear (1985), seeking to determine the definition of mental health, used an exploratory, descriptive design, to develop and administer an oral survey to whites, blacks and Indians in Robeson County. He found similarities in the way mental health was defined but varying degrees of emphasis that each group placed on the themes in their definitions. Locklear found that Lumbees identify a strong relationship between the body and mind. He also notes that Lumbees are much more tolerant of destructive behaviors (fighting, violence, substance abuse), but they do not identify these behaviors as poor mental health. Also, Lumbees did not choose to use the formal mental health services but preferred to rely on community support identified as family, elders, friends and clergy. West (2004) studied social anxiety in Lumbee adolescents and hypothesized that there would be higher levels of social anxiety in this population than in the general population and that this would negatively influence ethnic identity. However, she rejected both hypotheses. She did find higher social anxiety in Lumbee adolescents when they were confronted with new social situations, but did not address differences in social anxiety experienced outside the Lumbee community versus inside the Lumbee community. These studies reaffirm the role of stress and biculturalism and their relationship to poor health outcomes as well as the positive attitude towards community and family for addressing these concerns.

Other mental health issues among American Indians have been studied. In one recent descriptive study conducted by Baker et al. (2005), the authors reported higher levels of depression in American Indian women after they had given birth. In their study, *Prevalence of Postpartum Depression in a Native American Population*, Baker et al. found more postpartum depression in Lumbees than in the general population in Robeson County. While they noted that the scale (The Postpartum Depression Screening Scale, PDSS) used had not been validated in minority populations, and that there are several risk factors associated with postpartum depression, they used the PDSS and recommended it for practice with this population. The

authors did not determine or discuss the existence or role of pre-pregnancy depression rates in the study population. In the methodology section, the authors report that Lumbees participated in collecting the data as surveyors; however, there were no Lumbees involved in analyzing the data nor did members of the study population review the study results and conclusions. These omissions are especially significant since a research team at the University of North Carolina at Pembroke conducted this study. Clearly, Lumbee people continue to be marginalized in health research. In this study, the researcher is emic to the population and has the historical, socio-cultural context required for understanding a health-illness experience in this population.

One major research group has published the majority of the health research about Lumbees focused on chronic diseases including cancer. While the group's membership change based on the focus of the studies, Bell, who is a Lumbee male, participated in most of the studies that include Lumbees. The group's works detail Lumbee women's extensive use of tobacco products, high dietary in-take of fat, attitude towards cervical screenings, and high cardiovascular risk factors. Bell (1993), in his dissertation in the area of nutrition notes that the dietary patterns of Lumbees include high portions of fats and sweets. Spangler, Bell, Dignan and Michielutte (1997) in a descriptive study identifies the psychosocial factors related to cervical screening among Lumbees. They found that in addition to discomfort and embarrassment, factors reported in the general literature, Lumbee women include perception of disrespect from providers and cost as prohibitive factors for cervical screening. In 2005, the group including Bell published the largest study, the Lumbee Diabetes and Health Study (Farmer et al, 2005), a quantitative, descriptive study that surveyed 789 randomly selected participants aged 40 and older, who were enrolled members of the Lumbee tribe and had a working telephone. The survey instrument, based on the Center for Disease Control and Prevention's (CDC) Behavior Risk Factor Surveillance System (BRFSS), was used to conduct a 20-30 minute telephone interview. They found that Lumbees engage in numerous behaviors known to increase cancer risk including use of cigarettes and smokeless tobacco, overeating leading to obesity, and limited physical activity. However, their data also showed that Lumbees participate in screenings for various cancers and most identified

a regular health care provider. The study asked questions such as, “*Have you ever had a mammogram?*” The researchers did not ask about the frequency of participation in screening activities. The researchers recommend further studies to better understand the behavior patterns and recommend more community involvement in developing research. While not emphasizing behavior patterns, this study focused on understanding the experiences of Lumbee women who are breast cancer survivors.

Recently Bell and colleagues have published additional research that focuses on actions of individuals who have diabetes. The ELDER (Evaluating Long-term Diabetes Self-management Among Elder Rural Adults) study, a four-year study funded by the National Institute on Aging and the National Center for Minority Health and Health Disparities, is a population-based cross-sectional survey designed to comprehensively assess the self-care actions of older rural adults with diagnosed diabetes and the impact of these actions on diabetes control (Bell et al., 2005; Arcury et al., 2006). The Lumbees in Robeson County were one of the three racial groups studied. The study relied on self-report data, a limitation noted by the researchers. Bell and colleagues report higher incidence of depression in Lumbee study participants than in white or African Americans, though differences are not statistically significant (Bell et al., 2005, p. 828). Using the same database, Arcury et al. (2006) did not report any data by race or ethnicity, a major critical deficiency, since Lumbees were about 25% of the 701 study participants. Even though the study provides some information about actions of Lumbees living with a chronic disease, diabetes, it does not provide any details about the experiences of the study participants. This study of the experiences of Lumbee women breast cancer survivors does address these issues.

The value of elders and the perception of Lumbees toward elder abuse were explored by Hudson, Armachain, Beasley, and Carlson (1998). These findings were part of a large study proposed to determine the public’s definition of elder abuse. The subjects for the study included participants between the ages of 45 to 64 and 65 plus from different regions and different cultural groups of North Carolina. The study design, a mixed-method study, deliberately included the two

largest American Indian tribes in North Carolina, the Eastern Band of the Cherokees and the Lumbees. The results showed that Lumbees and Cherokees have a more inclusive definition of elder abuse than the other cultural groups. Members from these two American Indian groups also expect more professional and especially community intervention to prevent elder neglect and/or abuse, and recommend more community interventions when abuse is suspected. These findings confirm the previously reported expectation of community in maintaining care but counter the previously noted acceptance of violence. Both Lumbees and Cherokees report examples of societal abuse against their people in response to the question, *“What other types of abuse have you encountered?”* The finding may be considered in the context of Dodgson’s and Struthers’ assertions that group historical grief and trauma become one’s own (2005), a finding of special interest to this study since understanding the experience of surviving breast cancer victims requires inclusion of the historical, socio-cultural context.

While the published research and that available in dissertations about the health of this population are limited, these research studies do provide a health context for this study. The excessive level of depression, participation in risky behavior and substance abuse are congruent with a people who have undergone the historical, social and cultural trauma as that of the Lumbees. The silver lining in the research is that Lumbee value kinship and community in addressing health concerns. This study differs from other health studies on the Lumbees in several ways: the population of focus is breast cancer survivors, and the purpose is to understand their experiences by listening to their oral stories, a culturally appropriate method for gaining understanding. This study was the first to focus on understanding the experiences of Lumbees with illness. As in many of the other reviewed studies, the researcher in this study is emic to the population.

Summary of the Lumbee: The Literature Review

Lumbees are a resilient people who have not only survived years of discrimination and racism but have maintained their tribal cultural identity while learning to participate in the mainstream American culture. The experiences of historical trauma are found in the origins of a people of mixed heritages working together as a group bound by place and kinship to form the largest American Indian tribe east of the Mississippi. The Lumbees use oral stories to communicate and instruct as they struggle to maintain self-identify, achieve equality, and continue a group identity in a black-white society. These struggles have resulted in marginalization and discrimination; yet, they also are the experiences and events that provide the historical, social and cultural context for understanding the Lumbees.

The health research provides a profile of a people who suffer from many health disparities including high infant mortality rates, shorter life expectancy, higher morbidity from chronic illness and who have limited access to culturally appropriate health care services. The health research about the Lumbees, while limited, provides a glimpse of how this context influences their health-illness experiences. The Lumbees suffer from many disorders including depression, substance abuse and chronic diseases, and, while they engage in high levels of risky behaviors, they also seek solutions from within their communities, have a lower tolerance for violence against the elderly but appear to be more accepting of this violence from group members with mental health issues, and will participate in health screening activities. The themes of biculturalism, struggle for justice and strong group and community identity are evident in the health research. It is clear that Lumbees are marginalized and have had limited influence in research studies as evidenced by the sparse health statistics and the lack of inclusion in the population studies.

This study focused on understanding Lumbee women breast cancer survivors by listening to their oral stories of this common illness experience. In addition, this study, the first to focus on the Lumbee's understanding of a common illness experience, is also the first conducted

by a Lumbee nurse researcher. Like some of the other studies, the researcher is emic to this population in that is she is a woman, a Lumbee and a nurse.

Understanding American Indian Women Breast Cancer Survivors

According to the National Cancer Institute (NCI), in the United States in 2007 more than 175,000 women were diagnosed with breast cancer and more than 40,000 women will die from the disease (2007). NCI estimates that more than 90% of all women diagnosed with breast cancer will survive with the disease for more than five years (2007). While breast cancer incidence rates have continued to increase since the 1980s, the death rate has decreased, meaning that more women will survive the initial diagnosis of breast cancer and learn to live with the disease (Curtiss, 2006). The relative survivor rates for all breast cancers in white women is approaching 80% at ten years (Curtiss, 2006). Because of these increased survivor rates, understanding women breast cancer survivors has recently become a research priority. While national studies indicate that American Indian women may have a lower incidence of breast cancer than white women in the United States, they have a higher mortality rate (NCI, 2007). Still many do survive. No research has been found about Lumbee breast cancer survivors and a very small body of literature about American Indian breast cancer survivors is available to inform this study.

Understanding Breast Cancer in Indian Women

Data about breast cancer in American Indian women is fragmented often because of the small numbers, lack of inclusion in national studies and misclassification of race (Kaur, 1999; Partin et al, 1999). The available data profiles breast cancer in the American Indians with lower but questionable incidence rates, less frequent mammograms and screening, more advanced stage at the time of diagnosis, and longer intervals from detection to clinical presentation than the general population (Gilliland, Rosenberg, Hunt, Stauber & Key, 2000; NCI, 2007; Partin et al, 1999). Most of the studies use Surveillance and Epidemiological and End Results (SEER) data that underestimates the incidence and mortality rates in American Indian women outside Arizona and New Mexico (Burhansstipanor & Digner, 2000). Joe (2004), using 2000 SEER data yet

commenting on the poor availability of data, reports that the breast cancer survival rate for whites is 86% compared to the survival rate for American Indians of 72 %. Chlebowski et al., (2005) reporting from the Women's Health Initiative (WHI) concludes that American Indian women are not at a statistically significant lower risk for breast cancer than white women. Comparing the results for the WHI with the SEER data, they confirm that American Indian women experience a higher incidence of breast cancer than reported in the SEER data (28 cases/10000 per year compared to 16 cases/10000 per year) (p. 445). Thus, the breast cancer incidence, mortality and survival data are questionable but indicate that this is a significant health issue for American Indian women.

The scant data about breast cancer in American Indians in North Carolina is equally questionable. The North Carolina Center of Health Statistics and the North Carolina Office of Minority Health and Health Disparities (1999, 2006), and Yankasas, 2005) report the same problems with breast cancer data in the American Indian population in North Carolina. They found incomplete databases and overall unreliability of population counts. This is especially important when computing age-adjusted rates since the American Indian population is younger than the general population, a significant concern in determining breast cancer incidence, mortality and survival rates. In an unpublished study conducted by the North Carolina Cancer Register, the rates of breast cancer in American Indian women in North Carolina appear to approach the same levels of breast cancer in African American women (Personal communication, Yankasas, 2007). The Center of Disease Control National Center for Health Statistics reported the annual age-adjusted mortality rates for American Indians in North Carolina as 23.5/100,000 compared to the national rate for American Indians as 13.6/100,000 (2004). The difference in this data can be partially explained by the use of the age-adjusted 2000 standard general population, a new method of reporting to be used in reporting health statistics in the future (CDC, 2004). For this study, the incidence and prevalence rates are very important because of the high percentage of American Indians in North Carolina who identify as Lumbees. No data on incidence or survival rates among Lumbee women is available. However, as noted, data on breast cancer screening

behaviors by Farmer, Bell and Stark (2005) revealed that 86% of Lumbees had had at least one mammogram but no information on the frequency was provided (p. 637).

Therefore, the data about breast cancer in American Indian women in the United States and in North Carolina is limited and questionable. There is no clear statistical data on breast cancer in the Lumbee population, and information about their participation in breast cancer screening is incomplete. There is no information on breast cancer survival rates, time from symptom to clinical presentation, or selection of treatment modalities available for the Lumbee population.

Understanding the experiences of breast cancer survivors through nursing research.

Most nursing research focuses on breast cancer screening or end-of-life care, and there is a small body of nursing research on breast cancer survivors. Farmer and Smith (2002) published a conceptual analysis on breast cancer survivorship. Reviewing 50 references from medicine and nursing, they concluded by defining breast cancer survivorship as the “process of living through the cancer experience beyond cancer; therefore, survivorship is the process of individuals’ lived experiences” (p. 783). While logically noting the antecedent of cancer diagnosis, they identified consequences in physical, psychosocial, spiritual and socioeconomic areas.

The nursing research on breast cancer survivors can be divided into two groups: the experience and the effects of actions on the person’s responses to breast cancer. Studies that sought to illuminate the experience of surviving breast cancer studied the relationship between pre-determined variables and interventions. The specific variables included emotional distress (Knob, 2002), uncertainty (Wonghongkul, Moore, Musil, Schneider & Deimling, 2000), function (Samarel et al, 1998) symptom management (Samarel, Fawcett, Davis & Ryan, 1998) and loneliness (Samarel, Tulman & Fawcett, 2002). The actions are either actions selected by the woman or professional nursing interventions. Two professional interventions were used most often; they were support (Samarel, Fawcett & Tulman, 1997; Wilmoth, Tulman, Coleman, Stewart and Samarel, 2006) and education or a combination of support and education (Sandren, McCaul, King, O’Donnell & Foreman, 2000; Samarel, Tulman & Fawcett, 2002; Coleman et al, 2005).

Meraviglia (2006) conducted a descriptive, correlational study of the role of spirituality in 84 white, middle-class, educated, married females who had been diagnosed with breast cancer. She included meaning and action (to pray or not to pray) in her study. She found that spirituality, defined as meaning of life and prayer, had positive mediating factors for physical and psychological response. Only one of the action/intervention studies included women who had survived breast cancer more than five years (Meraviglia, 2006). However, the information derived from these research studies will be useful in understanding the themes that emerge for this study of the experiences of Lumbee women with breast cancer.

The other group of nursing research focuses on the experiences of the women. All of these studies use a qualitative design. Moch (1990) conducted the landmark study of experiences of women breast cancer survivors within 4-18 months of the diagnosis. Using Newman's framework, she identified five themes: getting information and making choices, coping with physical aspects, dealing with lack of control or possible reoccurrence, being hopeful, changing relatedness, and identifying meaning (p. 1430). Richer and Ezer (2002) studied the meaning assigned to the experience of chemotherapy in 10 women and found that both existential and situational meaning were an integral part of the experience. The grounded theory study identified two intrapersonal dimensions (*living in it* and *living with it*), two strategies of coping (put it aside and life lines) and moving on, a phase when women started to think about the future. Luker, Beaver, Leinster and Owens (1996) purposed to determine the meaning of illness within the context of breast cancer. In their study, women at the time of diagnosis and within 24 months of diagnosis matched their coping strategies with meaning statements. The authors report that the meaning of the illness for the women did not change during the study period. Boehmke and Dickerson completed two studies using the same data set of 30 women newly diagnosed with breast cancer. The first study, using a phenomenologic approach, examined the lived experiences of managing symptoms (Boehmke & Dickerson, 2005). Six themes emerged: (a) symptoms experienced were congruent with the type of treatment, (b) surgery resulted in minimal pain, but numbness and disfigurement were of great concern, (c) women undergoing

chemotherapy experienced nausea and hair loss, (d) while receiving Paclitaxel, the most distressing symptoms were bone pain and peripheral neuropathy, (e) women often described how the symptoms affected their quality of life and functioning, and (f) women were distressed by the cognitive changes experienced during treatment. In the second study, Boehmke and Dickerson (2006) completed a secondary analysis of the text from the previous study using a Heideggerian hermeneutic method examining the text for common meaning and shared experiences. All women in this study were white, middle class, still undergoing treatment, had no other comorbidities, and were confronting their first cancer experience. Four themes were identified: (a) changing health overnight, (b) erasing of a former self, (c) appraising of illness, and (d) approaching the future- now what? Using these themes, the authors proposed one constitutive pattern, transitioning from health to illness. The authors recommend replication of this research using women who were not demographically similar, and those with recurrent cancer. They also recommend exploring the social support network. McGrath et al (1999) interviewed women in rural Queensland, Australia. They found that women in rural communities operate within a strong, informal network of support.

The nursing studies of experiences of women with breast cancer reveal a combination of themes centering on their changing self and their changing lives and struggles with suffering inherent in breast cancer. The studies focused on women who were within two years of the diagnosis, and most participants were white, middle class women. The proposed study contributes to the body of nursing knowledge by studying Lumbee women breast cancer survivors, a different population than previously studied.

Understanding American Indian Women Breast Cancer Survivors through Nursing Research

Two studies with the goal of examining the experiences of American Indian breast cancer survivors were found in the nursing literature. Using stories of survivors from several different tribal groups, these studies provide different profiles of the experiences of the study populations. It is also critical to note that both researchers were in some way emic to the population, one being

an American Indian woman and one being a breast cancer survivor. Krebs (1997), an American Indian, undertook a grounded theory study, *Recreating Harmony: Stories of Native American Women Surviving Breast Cancer*. The study, a secondary data analysis of videotapes of 15 American Indian women breast cancer survivors who lived in an urban setting, examined the experiences of surviving breast cancer as perceived by the participants. The data were initially collected to enhance screening and early diagnosis for cancer in American Indian women. The breast cancer survivors were women from 13 different tribal groups and were defined as being free from breast cancer. As a result of the study, Krebs proposes a theoretical model of breast cancer survival for American Indian women. The theoretical model has one core category: recreating harmony. She further develops this category into four subcategories that support the process of recreating harmony: (a) gaining strength, (b) managing emotions, (c) maintaining positivity, and (d) moving on. Krebs recommends that other studies be conducted in this population that allow for women to be interviewed and re-interviewed as needed and be available to verify findings. She also recommends that future studies include expansion of topics and development of the sample with consideration of age, acculturation and place of origin (rural, reservation and urban). This study used the stories told by Lumbee women from a wide range of age and years since diagnosis and a broader definition of survivorship to include women who are not totally cancer-free. And the level of acculturation and place of origin were noted.

A second study of ten American Indian women breast cancer survivors from different tribal groups in the northern Midwest was completed by a breast cancer survivor who is not of American Indian origin. Kiser-Larson (1999), using Newmen's theoretical framework and methodology, studied the life patterns of interactions of the cancer survivors with their environment. In *Life Patterns of Native American Women Experiencing Breast Cancer*, Kiser-Larson included women whose time since diagnosis ranged from a few months to twelve years, with three of the women still receiving treatment. Kiser-Larson identifies three common dimensions or previous life patterns used to understand the experience of breast cancer: (a) deprivation, (b) loss and discrimination, and (c) connectedness through relationships. Without

exception these women describe an initial reaction to the diagnosis of breast cancer as “a life of disorder and chaos” (p. 102). The women describe a loss of control and the significant role of family to regain stability and increase their appreciation of life, the growth and insight they gained from the experience, and the role of spirituality in this process. The most common reported changes are expanded awareness of the spiritual dimensions of life, changing priorities of life and changes in career (p. 105). Most of the women comment on the importance of the opportunity “for them to not only tell about important people and events in their lives but to listen to their own stories as well” (p. 104). These findings are congruent with Newman’s theory and the unitary-transformative perspective that allow for the pattern of person-environment to unfold. Kiser-Larson reflects that she could not determine the significance of the role of the nurse-person interaction from this study. She did not address any of the findings or recommendations made in the Krebs study. However, Kiser-Larson’s findings are of particular importance since they are similar to findings found in studies about Lumbees: biculturalism, intense kinship and group identity, and struggles of equality.

Both Krebs’ and Kiser-Larson’s studies provide support for and work to inform this study. Both focus on the experience of American Indian women breast cancer survivors through their stories and oral accounts. While Krebs defined the breast cancer survivor as one who is free from cancer, Kiser-Larson used a broader definition and included some who were still undergoing treatment. Krebs developed a model to understand the experience of surviving breast cancer from the woman’s perspective, while Kiser-Larson used the women’s reflections of past experiences to explore their understanding of the experience of breast cancer. Neither of these models have been tested or reviewed by others who represent the American Indian population. In this study, the researcher sought to understand the experiences of Lumbee women with breast cancer through the stories they share, allowing the researcher and the women to connect and better understand how together they co-create their lives and world.

Understanding the Experiences of American Indians Through a Nursing Framework

When assessing experiences, it is essential to understand one's worldview and how the culturally constructed view of health determines an individual's views of illness and choice of treatment. Fawcett (2000), after noting that *frameworks* and *models* are synonymous, declares, "everything that a person sees, hears, reads and experiences is filtered through the cognitive lens of some conceptual frame of reference" (p. 15). Conceptual models have been used to study human phenomena, guide nursing practice, and develop nursing knowledge. Therefore, based on Fawcett (2000), and indeed supported by conventional wisdom, American Indians would also use a conceptual framework to experience and understand the world. Both nursing and non-nursing researchers studying American Indians agree that their worldview requires historical understanding (Bindler, Allen & Paul, 2004; Struthers & Lowe, 2003), and inclusion of the role of spirituality (Lowe & Struthers, 2001; Lowe, 2002, Struthers & Lowe, 2003; St. Clair, 2005), connectedness to kin, community and place (Burhansstipanov, 2005; Canales, 2004; Hill, 2005; St. Clair, 2005) and harmony (Burhansstipanov, 2005; Lowe & Struthers, 2001, St. Clair, 2005). The Conceptual Framework of Nursing in the Native American Culture (CFNNAC) strives to integrate a worldview of nursing and American Indians and provides a framework for nurses working with American Indian populations.

The Conceptual Framework of Nursing in the Native American Culture (CFNNAC) reflects the worldview of American Indians. Based on the premise that nurses from different cultural groups have different worldviews, the participants at the third American Indian Nursing Summit, "Gathering our Wisdom: American Indian Nursing III", were challenged to define the essence of Native American nursing (Struthers & Littlejohn, 1999). Using panel discussions and focus groups, participants affirmed that caring is a central theme in nursing, but added that six additional themes are essential to the American Indian nurse: tradition, respect, connection, holism/holistic, trust and spirituality. Building on this research, Lowe and Struthers (2001) repeated the process in 1998 at the fourth American Indian Nursing Summit, but asked that the themes of the previous year be reconsidered as they explored the themes proposed. In 1998 the

themes were reaffirmed and delineated and ultimately a conceptual framework was developed (Lowe & Struthers, 2001, p. 280) to encompass these seven themes: caring, traditions, respect, connection, holism, trust and spirituality.

The CFNNAC was developed using a culturally appropriate process including oral stories, circles, collaboration, inclusion and reflection. In writing about the initial formulation of the CFNNAC, Struthers and Littlejohn (1999) noted the value of circles and oral accounts, especially stories in the American Indian worldview. They further commented, "This is dissimilar to Western culture which is recorded and perceived to be linear in nature. In light of the previous mentioned factors, a separateness exists between the two cultures" (p. 132). The worldview that allows for co-creating is evident in the first meetings developing a model. The directions to the conference participants were to "incorporate traditional storytelling as a method to evoke dialogue within the group [and] allow the stories to emerge in order to lift out the essence of Native American nursing" (Struthers & Littlejohn, 1999, p. 132). Their two year, two-step process allowed participants from 39 tribes to ponder the essence of American Indian nursing. Thus, the CFNNAC is not only designed to reflect the essence of American Indian nursing but also the essence of American Indian culture used in the development process.

American Indian nurses have proposed that the Conceptual Framework of Nursing in the Native American Culture (CFNNAC) is the first culturally appropriate nursing conceptual framework designed by and for a particular ethnic group (Struthers & Lowe, 2003). In 2000, the nurses at the 10th annual American Indian Education Conference called for further research using this framework, including validation of the model's dimensions, characteristics and components with American Indian clients. Though it is recommended for use by American Indian nurses and nurses of other cultures whose focus are American Indian people, this researcher found no studies using the CFNNAC to understand the nursing needs of an American Indian population.

Summary of the Review of the Literature

The review of the relevant literature provides the rational, historical and experimental contexts for this study. In order to promote understanding of the experiences of Lumbee women

breast cancer survivors, the literature situates them within their historical, socio-cultural and health context. Lumbees are a resilient people who have a strong oral and written history of disruptive events. Most historians agree that they are a people of mixed origins who have an intense attachment to kin and place. The Lumbees have survived numerous hardships to form as a resilient people who maintain their tribal and cultural identity while learning to participate in the broader American society. Their struggles to self-identify, achieve equality, and survive in a black-white world as a different people are communicated and embodied by individuals. The context of resilience, history, cultural milieu, and deprivation influence their experiences when they encounter an illness.

The health research provides a profile of a people who suffer economic and health disparities. Lumbees experience high levels of poverty, low education attainment, and frequent engagement in risky behaviors. Despite the limited health statistical data, it is clear that Lumbees have high infant mortality rates, shorter life expectancies and higher morbidity from chronic illness than the general population and have limited access to culturally appropriate health care services. No studies were found that purposed to understand any of the illness experiences of Lumbee people.

National and state research about breast cancer is used to develop the context for Lumbee women since data and research on this population is limited. Even the data about breast cancer in American Indian women in the United States and in North Carolina is limited and questionable. The nursing studies of experiences of women with breast cancer reveal a combination of themes centered on their changing self, their changing lives and the struggles with suffering inherent in breast cancer. The nursing research about the experiences of American Indian women breast cancer survivors is limited to two studies that centered on different aspects of the experiences, used different definitions of a breast cancer survivor, and focused on populations from different tribal groups. This study used the recommendations of the aforementioned research to contribute to the nursing knowledge by including women at different ages who live in urban and rural settings, using the broader definition of breast cancer survivor

and seeking to understand the experiences of the women, all from the same tribe, in the study. In this study the researcher sought to understand the experiences of Lumbee women with breast cancer through the stories they share based in the historical, socio-cultural context (horizons) of both the researcher and the women, allowing them to connect and to better understand how together they co-create their lives and world.

While conceptual models have been used to study human phenomena, guide nursing practice, and develop nursing knowledge, the Conceptual Framework of Nursing in Native American Culture (CFNNAC) is the first framework developed for a specific cultural group. The framework provides a nursing reference for meeting the nursing needs of American Indian people. Developed by American Indian nurses who used a culturally appropriate process in so doing, the CFNNAC has been recommended for use with American Indian populations as part of the process for further development.

CHAPTER 3: THE METHOD OF INQUIRY

The purpose of this interpretive study was to understand the experience of surviving breast cancer for Lumbee women through the stories they have shared. Nurses have recognized that health care decisions are influenced by many factors including the person's understanding of the illness experience (Allen, 1995; Benner, 1999; Phillips, 2007). While it is recognized that the results of interpretive studies cannot be generalized, they can enhance nurses' understanding of the experience providing the foundation for creating possibilities of nursing interventions. In this study, the interpreter sought to understand the experience of surviving breast cancer of Lumbee women through a secondary analysis of texts of stories they have told.

This chapter will consist of two major divisions: (a) philosophical hermeneutics: a research process, and (b) philosophical hermeneutics: applied in research. First, the chapter includes a detailed discussion of philosophical hermeneutics as a process of nursing inquiry with (a) an overview of philosophical hermeneutics (b) a rationale for choosing the method: philosophical and theoretical substantiation, (c) background of philosophical hermeneutics, and (d) philosophical hermeneutics as a research process. In the second major division, philosophical hermeneutics: applied in research, the reader will find a discussion of philosophical hermeneutics used in this study of historically produced texts, including (a) the process of inquiry, (b) sampling and subjects, (c) data gathering strategies, (d) researcher as instrument, (e) protection of human subjects, and f) the hermeneutic circle.

Philosophical Hermeneutics: A Process of Inquiry

Overview of philosophical hermeneutics

Philosophical hermeneutics, as proposed by Hans-Georg Gadamer and developed by nurse researchers as an interpretive qualitative research approach, is used to understand the experience of surviving breast cancer of Lumbee women. Philosophical hermeneutics allows for understanding to occur within and between traditions, times and cultures (Benton & Craib, 2001). In philosophical hermeneutics, understanding, a process that requires reflection on the familiar and the alien, is recognizing the meaning of an experience for the one who has or has had the

experience (Linge, 2004). This process recognizes that women who have shared their stories own their truth and that the language they use gives meaning to the experience and reveals the historical consciousness, the horizon, of the women involved (Gadamer, 1975; Hekman, 1986; Fleming, Gaidys, & Robb, 2003). Philosophical hermeneutics also acknowledges the reader, or interpreter, as a historical being who is seeking to understand the experience of the other, not to replicate that experience, but to reflect upon it and to change as a result of this new understanding (Allen, 1995). According to Gadamer, as cited by Linge (2004, p. xi) understanding is ontological, “the question is not what we do or what we should do, but what happens beyond our willing and doing.” In this study, the historically situated texts of the stories of Lumbee women about their experience of surviving breast cancer will be read and interpreted by the historically situated Lumbee nurse researcher to yield an understanding of the experience for the Lumbee nurse.

Rationale for choosing method: philosophical and theoretical substantiation

Nurses use interpretive inquiry to understand those who receive nursing care. In practice, nurses use the nursing process to listen to the person's needs which are at least at first alien, and fuse that understanding with the familiar nursing knowledge to plan nursing care. Nurse researchers, in qualitative research, explore human behaviors and search for understanding by interacting with the study participants through observations and/or dialogue (Fleming, Gaidys & Robb, 2003; Giuliano, 2003; Maggs-Rapport, 2001; Munhall, 2001; Newman, 2005). Philosophical hermeneutics as proposed by Gadamer is the research process selected for this study because it is congruent with the study's primary purpose.

In addition to its congruency with this study's purposes, Gadamerian philosophical hermeneutics is congruent with a nursing worldview and the Lumbee worldview. This congruency is found in the emphasis on understanding and the practical nature of understanding, the acceptance of human beings as active constructors of truth and meaning expressed in dialogue, the influence of the historical, socio-cultural context on the person, and, the expectation of change (Alligood & Fawcett, 2004; Darbyshire, Diekelmann & Diekelmann, 1999; Fleming,

Gaidys & Robb, 2003; Linge, 2004; Magg-Rapport, 2001, Phillips, 2007). The expressed tenets of philosophical hermeneutics are that understanding can only be accomplished in historical context, that language is contextually developed, and that understanding is productive (Allen, 1995, Fleming, Gaidys & Robb, 2003; Gadamer, 1975; Maggs-Rapprt, 2001, Phillips, 2007). According to Gadamer, both the person who initially produced the text and the person interpreting the text are doing so within their historical context, inclusive of their prejudices (Allen, 1995; Gadamer, 1975; Linge, 2004). In this study, the historically produced text of stories about the experience of surviving breast cancer by Lumbee women was interpreted by one whose historical context is a Lumbee woman who is a nurse.

Philosophical hermeneutics is ontologically congruent with the simultaneous action worldview tradition, which will be explained below, and is a valid process for nurse researchers to gain understanding about the health/illness experience (Allen, 1995; Alligood & Fawcett, 1999, 2004, Fawcett, 1993; Phillips, 2007). Alligood and Fawcett concluded that the hermeneutic tradition is consistent with nursing's simultaneous action worldview requirement that persons be studied "in continuous mutual exchange with their environment," (1999, p. 9) and that the assumption of holism and change are included. They further argue that the interpretive hermeneutic process actually facilitates nursing inquiry into the pattern of continual mutual exchange between the person and the environment since it allows the interpretation of meaning of the person/environment at a more concrete level. Phillips (2007) also emphasizes the congruence between nursing and interpretive hermeneutics, especially nursing practice. He stresses the importance of persons as owners of their truth and the importance for nurses to gain understanding as a foundation for nursing care. "In this way nurses and those we care for are tied together in a dialogue, or fused, in the process of understanding" (p. 91). The understanding gained from this study can be used to interpret the meaning of the experience for Lumbee women within their tradition. Understanding results from the fusion of horizons between Lumbee women's tradition, their experience as breast cancer survivors, and the interpreter's traditions of nursing and Lumbee culture.

In this study the phenomenon of interest was Lumbee women who are breast cancer survivors. In order to understand the meaning and truth of the experience of surviving breast cancer for Lumbee women, one must recognize these women as unit

ary whole beings, including their socio-cultural, historical context, who are in continuous relationship with their environment, and in Gadamerian terms, their traditions. As a result of this exchange, one is continually developing, expanding one's horizon. Likewise the same recognition is true for the interpreter who read and interacted with the text of Lumbee women's stories (Allen, 1995; Alligood & Fawcett, 1999; Darbyshire, Diekelmann & Diekelmann, 1999; Fleming, Gaidys, Robb, 2003; Gadamer, 1975; Maggs-Rapprt, 2001). The nurse researcher was changed, and her horizon was expanded in the process of understanding. This new knowledge can then be used to understand the possibilities of future nursing care, thus expanding the tradition of nursing. Geanellos (1998) claims that, " For Gadamer, knowledge is always shared...An intersubjective perspective of understanding presents knowledge as co-determined because knowledge does not reside within an individual but within a tradition" (p. 240).

In philosophical hermeneutics one acquires understanding through language. Gadamer (1975) reasoned that we, as humans, are not only born into a historical and cultural context, but that we are linguistic beings from birth. Language is not just a tool of exchanging ideas, but reflects one's being. Moreover, language provides the meaning one assigns to experiences (Gadamer, 1999; Heckman, 1985). Freeman (2007) summarizes the relationship between a person and language, "We speak to understand, and it is because we are originated to the world as understanding beings that we are always in dialogue with it" (p. 925). Gadamer emphasizes that while we use language to express our own truth, it is not an individual possession but that a common language must be worked out before understanding can occur. He concludes, "To reach an understanding with one's partner in a dialogue is not merely a matter of total self-expression and the successful assertion of one's own point of view, but a transformation into a communion, in which we do not remain what we were" (p. 341). Thus, by means of the hermeneutic process, the nurse interpreter (historically produced) interacting with the text (historically produced) of the

stories of Lumbee women about their experience as breast cancer survivors, gained understanding of their experience. This was accomplished in dialogue by a fusion of the horizon of the interpreter with the horizons of the Lumbee women.

In addition to its congruence with the simultaneous action worldview, philosophical hermeneutics is congruent with Lumbee culture, thus providing a sound philosophical process for this study. Philosophical hermeneutics as developed by Gadamer and Lumbee culture have parallel tenets in that understanding is achieved through language and a fusion of horizons. In philosophical hermeneutics understanding is achieved by conversation between the interpreter and the person who is experiencing the phenomenon or the text produced by that person (Gadamer, 1975). The Lumbees, a primarily oral society, value oral conversation and use stories to impart understanding and to instruct (Deese, 2002; Dial, 2006; Maynor, 2005). Most often the answer to a question is a story, usually about a family member, church or tribal leader. One is not expected to use the story as specific instructions, but as a guide in creating or finding one's own understanding. Both the storyteller and the listener are expected to attend to the process. In Gadamerian hermeneutics understanding is a process achieved by the fusion of horizons that require a deliberate act and result in a new creation for those involved (Gadamer, 1975). The Lumbee are a people whose experiences have required that they continually fuse the horizons of their people and place with the horizon of people from other cultures. Only by knowing this can one understand who the Lumbees are and how the people are who they are. Therefore, Gadamerian hermeneutics provides a culturally congruent process for studying and gaining understanding of Lumbee women who are breast cancer survivors.

By way of summary, this inquiry was informed by nursing's simultaneous action worldview, Lumbee culture and Gadamer's philosophical hermeneutics. These converge in the following ways: (a) humans are unitary beings, (b) truth is influenced by environment especially historical context, (c) language and dialogue, expressions of one's being (one is one's language), are critical components of understanding, and (d) change is productive of greater complexity (co-creation, personal becoming, fusion of horizons). Therefore, philosophical hermeneutics as

described by Gadamer is congruent with nursing's simultaneous action and Lumbee's worldviews, and thus was an appropriate methodology to use in a nursing study that sought to understand the experience of surviving breast cancer for Lumbee women.

Background of philosophical hermeneutics

Hermeneutics is both a historical and contemporary concept. The etymology of hermeneutics is found in Hermes, the Greek messenger of the gods. Hermes had to be conversant in both the language and world of the gods and the language and world of mortals to whom the messages were directed (Hamilton, 1942). His tasks required that he understand the god's original meaning and interpret it to mortals (Mueller-Vollmer, 1985). Hermes's eloquent use of language to inform, convince, and persuade allowed him to cross the boundaries of time and place (Hamilton, 1942).

The etymology of hermeneutics in antiquity provides a foundation for contemporary hermeneutics. Modern hermeneutics is a philosophical discipline and a general process that contributes to the development of thought in a wide range of disciplines including the human sciences (Mueller-Vollemer, 1985). The development of hermeneutics as a philosophical discipline has its genesis in modern Germanic thought beginning with Schleiermacher who postulates that parts of the text can only be understood in context, in the whole (Howard 1982; Gadamer, 1975; Mueller-Vollemer, 1985). This study was based on the most recent of those schools of thought, philosophical hermeneutics as proposed by Hans-Georg Gadamer (Howard, 1982; Linge, 2004).

Gadamer (1900-2002) states that the purpose of philosophical hermeneutics is to understand. He notes:

The Individual case does not serve only to corroborate a regularity from which predictions can in turn be made. Its ideal is rather to understand the phenomenon itself in its unique and historical concreteness. ... to understand how this man, this people or this state is what is has become—more generally, how has it happened that it is so. (Gadamer, 1975, p. 6).

By using the philosophical hermeneutic process one is seeking to understand the historical experience of another from within their tradition (Gadamer, 1985). Understanding is ontological, and one is understood through language and in the tradition. This is accomplished by the fusions of the author's and interpreter's horizons, thus, allowing the interpreter to have a wider, truer vision of self and the other and to project ahead (Gadamer, 1975, p. 270; Gadamer, 1985, p. 270; Phillips, 2007). In this study, the nurse interpreter developed an understanding of the experience of surviving breast cancer by fusing her horizon with that of the Lumbee women.

Gadamerian philosophical hermeneutics is based on the writings of Dilthey, Husserl and Heidegger (Fleming, Gaidys, Robb, 2003; Gadamer, 1975; Maggs-Rapprt, 2001; Mueller-Vollemer, 1985, Phillips, 2007, Welch, 1999). Dilthey (1833-1911) is recognized as the founder of human science, defined as a science in which the subject is the reality of humans that "...originates from the interaction between lived experience, understanding of other people, the historical comprehension of communities as the subject of historical activity and insight into objective mind" (Dilthey, as cited in Mueller-Vollemer, 1985, pp. 151-52). Dilthey focused on the coherent whole of the lived experience, which he characterizes as constantly changing and building upon other experiences (Mueller-Vollemer, 1985). Husserl (1859-1938), the founder of phenomenology, built upon Dilthey's thinking by focusing on the description of the lived experience as an event that is lived and a valid truth as described by people involved in the experience (Hekman, 2003; Howard, 1982; Mueller-Vollemer, 1985). While the phenomenological viewpoint provides a foundation for studying the lived experience of surviving breast cancer, its aim is explanation, not understanding. Husserl's perspective is epistemological, asking, "What do we know?" For example, from an epistemological perspective the purpose for this nursing inquiry would have been to discover and learn about the intricacies of breast cancer survivorship, not understanding the experience of breast cancer survivors. In contrast, Heidegger (1889-1976), a student of Husserl, postulated an ontological perspective, changing from explaining to understanding, not just describing the event but interpreting for meaning (Darbyshire, Diekelmann

& Diekelmann, 1999; Fleming, Gaidys & Robb, 2003; Howard, 1982; Maggs-Rapport, 2001; Mueller-Vollemer, 1985).

This study asked an ontological question. The researcher sought to understand the experience of Lumbee women who are breast cancer survivors, or to use Heideggerian language, sought to understand 'being-in-the world' (Heidegger, 1999). As one being-in-the world, *Dasein*, one's experiences, practices, histories and traditions give meaning to life and are one's own truth (Heidegger, 1999). To Heidegger, *Dasein* is a human being immersed in a tradition from which he/she is inseparable, a condition Heidegger called *thrown into the world* (Heidegger, 1999). *Dasein* is involved with and changed by the experience of living (Darbyshire, Diekelmann & Diekelmann, 1999; Howard, 1982; Fleming, Gaidys & Robb, 2003; Heidegger, 1999). With the publication of his pivotal work, *Being and Time* (1927), Heidegger changed the discussion in hermeneutics from understanding as explanatory to understanding as part of who one is in the world, which is what is meant in this study when we use the term 'ontological'. Because of the nature of experience and tradition, where one is thrown into the world, understanding is personal, temporal, intentional and historical (Darbyshire, Diekelmann & Diekelmann, 1999; Howard, 1982; Fleming, Gaidys & Robb, 2003; Heidegger, 1999). Thus, truth for a Lumbee woman who is a breast cancer survivor is developed by her personal experiences and her traditions; her truth is embedded within her horizon. The source of knowing resided with each woman and was shared as she told her own story. Heidegger maintains that meaning and understanding are the same:

Basically, all ontology, no matter how rich and firmly compacted a system of categories it has at its disposal, remains blind and perverted from its own aim, if it has not first adequately clarified the meaning of Being, and conceived this clarification as its fundamental task...Understanding of Being is itself a definite characteristic of Dasein's Being. Dasein is ontically distinctive in that it is ontological (p. 279).

Understanding is ontological and is a characteristic of one's being-in-the-world. The ontological question asked about the phenomenon central to this study was, "What does it mean to have survived breast cancer and to be involved in the situation as a Lumbee woman?" Therefore, this

nursing inquiry was ontological because the purpose was to understand the experience of Lumbee women who are breast cancer survivors. For Heidegger and his student Gadamer, it is through language that *Dasein* is understood (Gadamer, 1975).

Heidegger and Gadamer agree that understanding and behavior are linked to a priori knowledge (historical consciousness) and that one interprets the world from one's own historical context (tradition) and experience, one's own horizon. Gadamer contends, "...the great horizon of the past, out of which our culture and our present live, influence us in everything we want, hope for, or fear in the future" (LInge, 2004, p. 9). For Heidegger and Gadamer, meaning and understanding are produced by the interaction between an individual and a situation. One's situation is composed of one's historical context and prejudices; one's horizon is everything which can be seen from a particular vantage point (Gadamer, 1985). The historical horizon imparts meaning in our lives without conscious effort. However, understanding requires reflection.

One's situation includes not only the pre-understanding one has including prejudices, but also the language used in expression. Gadamer (1999) clearly states that "...the interpretation of the world has been gained from life experiences and that is fundamental to our culture and linguistic tradition also remains alongside the other, and that in the end it constitutes what is superior for human action" (p. 354). Thus, understanding, culture, language and interpretation are bound. In this study, the language and stories told by a Lumbee woman reflected her cultural context, her understanding of the experience and her interpretation of the experience.

Philosophical hermeneutics as a research process

While others in the development of human science realize that one's truth is unique, influenced by tradition and historical context, Gadamer asserts that language is the key to self-understanding and the understanding of others. "...[W]e are drawn into the event of truth by tradition and through the medium of language; it is thus through the examination of language that we are able to understand the event of truth in the human science" (Gadamer, 1975, p. 446.) The words one uses to dialogue about an experience not only reflect one's historical consciousness but also reflect the meaning of the experience. Thus, language is a way of being in the world

(Allen, 1995; Gadamer, 1975). Having an experience and being changed by it do not require special knowledge or reflection; one's historical traditions and context effectively influence one's being and do not depend upon one being aware of the influence. To have effective historical consciousness is to be aware of the influences of culture, time, prejudices and experiences on one. This historical consciousness is known as *being in the hermeneutic situation*. Gadamer argues, "We are always within the situation, and to throw light on it is a task that is never entirely completed" (Gadamer, 1985, p. 269). Understanding of the situation is achieved by confrontation and reflection and allows one to project forward (Howard, 1982; Gadamer, 1975; Linge, 2004; Mueller-Vollemer, 1985; Phillips, 2007; Welch, 1999). In this study, the experience in question was surviving breast cancer. For the women, confrontation with the experience took the form of a taped interview. The woman revealed her truth about the experience in the story she chose to share and the language she chose to use. To understand this truth, the experience was related back to her as a whole being including her tradition and historical context. This constitutes the horizon of the person in the experience and is communicated and understood through language (Allen, 1995; Alligood & Fawcett, 1999; Fleming, Gaidys & Robb, 2003; Howard, 1982; Gadamer, 1975; Linge, 2004; Phillips, 2007). In this study, the Lumbee women who are breast cancer survivors have reflected upon the experience by telling their stories which have been converted to text. The interpreter interacted with the text to complete the philosophical hermeneutic process.

The researcher in this study purposed to understand the experience of surviving breast cancer for Lumbee women. The interpreter is a Lumbee nurse who shares the traditions of the Lumbee culture, but is less familiar with the experience of survivorship. The interpreter's understanding evolved by fusing the historical horizon of the text with the interpreter's horizon. Gadamer (1985) notes,

When our historical consciousness places itself into historical horizons, this does not entail passing into alien worlds unconnected in any way with our own, but together they constitute the one great horizon that moves from within and beyond the frontiers of the

present ...we must always already have a horizon in order to place ourselves within a situation...into this other situation we must bring ourselves (p. 271).

In this study, the interpreter is a Lumbee woman of the same era as the author of each text, and she is a nurse, thus bringing these two traditions to the hermeneutic situation, where she expanded her horizon.

Gadamer argues that acquiring this new horizon "...means that one learns to look beyond what is close at hand-not in order to take away from it, but to see it better within a larger whole and truer proportion" (p. 272). Thus understanding is the result of a deliberate process. To engage in the process leads to the interpreter's understanding that is also bound by effective-historical consciousness. The new horizon, gained by the fusion, is continually being formed as the interpreter changes and communicates with the text (Gadamer, 1975; Gadamer 1985; Linge, 2004; Phillips, 2007). Gadamer proposed the use of the hermeneutic circle to engage in the process of fusion of horizons (Gadamer, 1975).

The hermeneutic circle required the interpreter, from within her horizon inclusive of pre-understanding and prejudices, to interact with the text through questioning, not to reproduce the understanding of the author, but to produce the interpreter's understanding (Linge, 2004). The interpreter brought her own pre-understanding and prejudices, thus did not approach the text neutrally. According to Gadamer, one's prejudices "constitute the historical reality of one's own being" (1975, p. 266), and these have a greater influence than judgments reached through reasoning. Moreover, Gadamer declares that as soon as the interpreter read the text, she "...projects before [her]self a meaning for the text as a whole as soon as some initial meaning emerges in the text" (1975, p. 266). The hermeneutic process began when the interpreter deliberately reads the text that represents the participant's horizon, to answer a question. Gadamer notes,

Understanding begins...when something addresses us. This is the primary hermetic condition. We now know what this requires, namely the fundamental suspension of our

own prejudices. But all suspension of judgment and hence, a fortiori, of prejudices, has logically the structure of a question (1975, p. 266).

Interpretation is a circular movement between the reader's expectation, which emerges from her horizon, and the meanings within the text (Allen, 1995; Alligood & Fawcett, 2004; Howard, 1982; Mueller-Vollmer, 1985; Phillips, 2007). The interpreter, anticipating newness from the text, moved back and forth between the whole and the parts, constantly reflecting on the words the women used. This process continued each time producing more illumination as the interpreter's understanding deepened, until the emerging correspondence between the parts and the whole was achieved. The interpreter, being aware of the role of effective historical consciousness in acquiring understanding, considered the context of the Lumbee women who are breast cancer survivors who have told their stories as well as the interpreter's context. According to Allen (1995), "... the interpretation which results is a fusion of the text-and its-context with the reader-and-his/her context" (p.179). Referring back to Heidegger, Gadamer (1975) states,

...every revision of the fore-projected is capable of projecting before itself a new project meaning, that rival project can emerge side by side until it becomes clearer what the unity of meaning is that interpretation begins with fore-conception that are replaced by more suitable ones.. .This constant process of new projection is the movement of understanding and interpretation. A person who is trying to understand is exposed to distraction from fore-meanings that are not borne out by the things themselves. The working-out of appropriate projects, anticipatory in nature, to be confirmed 'by the things' themselves, is the constant task of understanding (pp. 236-7).

As there is no single place to begin the hermeneutic process, there is no ending as the movement between the part and the whole results in continual expansion of one's horizon, expanding understanding and producing new questions of the text.

Fundamentally, understanding is always movement in this kind of circle, which is why the repeated return from the whole to the parts, and vice versa, is essential. Moreover, this

cycle is constantly expanding, in that the concept of the whole is relative, and when it is placed in ever larger contexts the understanding of the individual element is affected (Gadamer 1975, p. 167).

In this study, the nurse researcher, the interpreter, did not seek to explain or describe the viewpoint of the participant (Lumbee woman who has experienced breast cancer) nor did the researcher attempt to validate or refute any preconceived answers. The interpreter realized that true understanding was acquired by overcoming the phenomenon's strangeness (experience of surviving breast cancer) and transforming it into something familiar (tradition of nursing), thus fusing the horizons. Gadamer maintains that "prejudices not only give the hermeneutic problem thrust, it is the means by which the truth about a phenomenon is established" (Maggs-Rapport, 2001, p. 377). By allowing the text to question the interpreter's fore-meaning and expecting the text to reveal something new, the interpreter moved from the whole of the text to the parts and back again until understanding was achieved. The interpreter's horizon was fused with that expressed in the text to produce an understanding of the phenomenon in question, the experience of surviving breast cancer in the Lumbee culture.

Understanding is productive, increasing the interpreter's mode of being-in-the-world by expanding her horizon (Allen, 1995; Gadamer, 2004). In this process, when working with a text, the interpreter first read the stories told by Lumbee women for meaning, practices and behaviors and to illuminate understanding (Allen, 1995, Fleming, Gaidys & Robb, 2003; Gadamer, 1975; Maggs-Rapprt, 2001; Phillips, 2007).

Since interpreters have different horizons, there are multiple understandings of the same experience (Gadamer, 1975). The truth of the experience resides with the women who are telling their stories. And though understanding is the fusion of the different horizons and will differ from horizon to horizon, it is not arbitrary. The text itself verifies the understanding and interpretation. Harmony between the parts and the whole must be achieved by finding a common language between the text and the interpreter. In this study, the interpreter is the researcher who is a Lumbee nurse who interacted with the text of the stories of the Lumbee women to understand the

experience of surviving breast cancer. The process began with the researcher's openness to dialogue with the text to understand the truth of the women's experiences.

Philosophical Hermeneutics: Applied in Research

The process of inquiry

Gadamer argued that understanding is acquired through a productive, deliberate interpretive process between the text and interpreter within the hermeneutic circle. However, he did not propose a specific mode for inquiry. Nurse researchers have designed a method to produce understanding using the hermeneutic process (Alligood & Fawcett, 1999, 2004; Fleming, Gaidys & Robb, 2003, Phillips, 2007). Alligood and Fawcett extrapolated from Allen (1995) the four-step methodology adopted for this study (Alligood and Fawcett, 2004).

The research procedure offered by Alligood and Fawcett (1999) addresses the hermeneutic process including the paradox of the hermeneutic circle: one only understands our part in life through our relationship with the world, and one only understands the world by reflecting upon the experience and one's pre-judgments about it. Using the four-step process delineated by Alligood and Fawcett (1999), the interpreter (a) identified a specific research question, (b) read the relevant text for meaning, (c) interpreted what was read, and (d) interacted with the text by reflective consideration of the text's context and the meaning of the words, "so that the interpretation that results is fusion of the text and its context with the reader and his or her context" (p. 10). Since understanding continuously expands, this process continued until there was harmony between the whole in context, the parts and the whole.

In this study, the nurse researcher, who is the interpreter, began by asking, "What do Lumbee women tell about the experience of surviving breast cancer?" of the text derived from the stories they shared. The interpreter read each story and the accompanying field notes for context and meaning. In this reading, the interpreter reflected on the text for context, meaning, practices and behaviors. She moved from the text to her horizon as a Lumbee and a nurse, all the while reflecting until an orderly, consistent interpretation, harmony, was achieved. In this process the

interpreter's understanding was illuminated. As the interpreter's understanding deepened, she wrote her understanding of this story, thus, producing new text.

Though there are many valid interpretations of a text, right understanding is not arbitrary. The interpretation must exist within the realm of possibilities, and the text.. Alligood and Fawcett (2004) note that "The text itself serves as a check on the interpretation" (p. 10). Meaning ascribed to words, practices and behaviors was consistent between the whole and the parts as well as congruent with the text's historical context (Fleming, Gaidys and Robb, 2003; Phillips, 2007). The interpreter's reasoning was clearly recorded at each step of the hermeneutic process and was consistent as she moved from the whole to the part and back to the whole (Allen, 1995). In this study, the text, the oral accounts, the interviewer's field notes and the researcher's journal were available and used All of these were considered and used to acquire understanding.

Sampling and subjects

In this study, a set of sixteen verbatim transcripts of stories of Lumbee women who have survived breast cancer was used. These stories were audio recorded during interviews of women collected in a previous project, NABCR-Native Breast Cancer Registry (NABCR). In the NABCR, funded by the National Cancer Institute, oral accounts were collected for the purpose of documenting the experiences of Lumbee women about being diagnosed with breast cancer. (Oral histories of social and education concerns of Lumbees have been collected and achieved. The NABCR is the only compilation of stories that focus on health that have been collected and archived to date.) The researcher of this study was a co-investigator in the NABCR.

The NABCR did not have a specific research question or methodology for the data analysis included in the project design, but there was a goal of storing these for future generations. To this end, the NABCR was approved by the Institutional Review Boards at The University of North Carolina at Chapel Hill (UNC-CH) and The University of North Carolina at Pembroke (UNCP). The women interviewed granted permission for future study of the data. With the consent of the Lumbee women, the taped interviews and verbatim transcripts were stored at UNC-CH and UNCP. Many of the women ended the interviews with a comment that they hoped

that their stories would be helpful to someone else. This study honors the desires of the women by interpreting their experiences so that nurses can gain understanding and provide culturally appropriate nursing care to Lumbee women who are breast cancer survivors.

For this study, stories of sixteen women were selected from a pool of twenty-nine stories as the data set. These were selected based on characteristics of the interviewee, the interview, and the interviewer. The researcher in this study, as co-investigator of the NABCR, had selected the women for the project. Using a convenience sampling to identify women, she selected women to be interviewed using the primary and secondary cultural characteristics of age, educational level, health-illness experience and origin proposed by Purnell and Paulanka (2003). All sixteen stories selected for this study were provided by women who met the criteria of being breast cancer survivors and Lumbee.

After collecting the first ten oral histories, the NABCR team decided to change to a less structured interview. This choice allowed women more freedom to discuss their experiences related to breast cancer instead of focusing on the diagnosis. The sixteen interviews selected for this study project were all collected using the less structured interview format.

The original intent was to capture the stories as oral histories. To avoid any biases from influencing the stories, the decision was made that the interviews would be conducted by someone from the cultural group not yet known to the women. Since the researcher, and more importantly her family, is a prominent member of the Lumbee community, the project team decided that she would not collect the interviews but would select and assist with the training of the interviewers. Using the cultural model of younger women asking for information from older women, younger Lumbee women were trained to conduct the interviews. The sixteen stories selected for this research project were all collected by the same interviewer using the revised interview guide.

Data-gathering strategies

A Lumbee woman who was educated at the baccalaureate level and trained by the researcher and a member of the staff of the North Carolina Center for Oral History conducted the

interviews. The women were contacted by the interviewer prior to the interview date, the project was explained and a date and place was established for the interview. After the participant had given informed consent to be interviewed, separate consent was received to tape the interview and to take a picture of the study participant. All agreed to have the interview taped, but several women elected not to have their picture taken. Brief field notes accompany the interview. Interviews were transcribed verbatim by a trained transcriptionist.

The interviewers had been trained to observe cultural norms in the interviewing process. Since one's family heritage and location of one's home place are important to the Lumbees, the interviewer was allowed to share this information with women. The interviewer was instructed to observe the cultural ways including periods of silence and being respectful of changes made in the interview process. For example, in one interview an electrical storm is heard in the back ground. The woman asked for the tape to stop and the interview to be paused while "the Lord is doing his work." Since the interviewer was a younger Lumbee woman, the interviews have the cultural congruency of older women using stories to teach. Thus, the texts were produced within the Lumbee tradition of older women telling stories to younger women.

The researcher as instrument

Within hermeneutic phenomenology, the researcher is not an objective bystander, passively observing participants to maintain objectivity. In this study the researcher actively engaged with the text of the stories as she sought to clearly understand what the Lumbee women were trying to portray. This engagement occurred through conversation between the text and the researcher.

The experience of surviving breast cancer was not alien to the interpreter of this study. Though she is not herself a breast cancer survivor, she has several family members who are breast cancer survivors. Also in her practice, she has provided care to many women with breast cancer. The researcher was familiar with the stories of women who were cancer survivors. As a member of the research team studying the use of mammography in American Indian women in North Carolina, Carolina Mammography Registry- Native American Project, she visited with many

Indian women's groups and Indian church across North Carolina. True to native traditions, she heard many stories from American Indian women about cancer including some stories of women who were breast cancer survivors.

The interpreter (researcher) is familiar with the world of nursing since she has been practicing nursing since 1973 and has earned advanced degrees in nursing and in public health. She has practiced nursing for thirty-five years, more than twenty of these in Robeson County. The interpreter has been involved in other research projects that included Lumbees as participants. In this study, the interpreter used her familiar horizon that includes her experiences as a nurse, a nurse in the Lumbee community, and a Lumbee woman reared in the twentieth century with the unfamiliar horizon of Lumbee women who are breast cancer survivors to produce understanding.

Protection of human subjects

This project was reviewed and approved by the Institutional Review Board for Protection of Human Subject of East Carolina University. Since this was an analysis of data previously collected, an exempt review was allowed. Confidentiality is always a difficult matter when doing research in one's own community. One must be diligent to assure privacy. Procedures to protect the confidentiality of participants included using aliases for each woman and providing only necessary contextual information about them in the research journal.

To assure anonymity and to continue to protect the rights of the women, the interpreter downloaded the manuscripts to a secure, private computer. The researcher reviewed the transcripts for accuracy by simultaneously reading the transcripts while listening to the audio recordings. With this reading, all identifying or potentially identifying information was removed from the transcripts. The original tapes and transcripts were returned to a locked, fire-proof cabinet in a secure office.

Next, demographic information about the women's age, date of diagnosis, and place of residence was placed in a separate folder before loading the remaining data as a case file into NVivo 8. This information included primary and secondary cultural characteristics identified by Purnell and Paulanka (1998). In this study these were age, origin (Lumbee), educational level,

urban versus rural residence and length of time away from the country of origin (living outside a Lumbee community). In addition to these characteristics, data was provided about the length of time since diagnosis and the age at diagnosis. The casebook containing this information is available to the reader in Appendix A.

The hermeneutic circle

Each of these women has a story to tell about surviving breast cancer. The women related many stories that culminate in the total experience which has had a lasting influence on their *being-in the world*. While there are many similarities in their stories, each story belongs to only one woman. True to the hermeneutic tradition, the researcher also had her own story, her horizon, which she used to understand the women's experiences.

Since nurses use their understanding of a person's health/illness experience to design nursing care, it is critical that nurses actively seek to understand the patient's experience. The hermeneutic process began with identifying the specific research question, "What do Lumbee women tell about their experiences of surviving breast cancer?"

The researcher used NVivo 8, qualitative computer software, to track identified topics (nodes), to group text, and to move between the sixteen interviews as a set or parts of the interviews associated with identified topics. The researcher also used NVivo 8 to log the research process, record her understandings throughout the research process and to develop a casebook of participant demographics.

After listening to the audiotapes and validating the transcripts, the researcher imported these along with the field notes into NVivo 8. A second reading of the full set of transcripts was completed incorporating the coding techniques available in NVivo 8. Since the researcher's is a Lumbee and shares much of the historical context with the women the process of understanding, gained by a fusion of horizons, began with the identification of topics and coding of the text. As the text was read, the researcher reflected on what each woman was discussing, identified topics, and associated the text with a node that defined and explained the properties of the node. For

example, church was a node defined as “any mention of attending church or associating with people from church.” Once a node was defined, it was used to code additional text.

In the interview, each woman provided rich stories of her family, life within the Lumbee community, and other health conditions as well as her reflections on breast cancer. Often a woman would provide information about breast cancer while telling a story about a family member. Therefore, the sixteen texts were read in their entirety for meaning and initial identification so topics as indicated by the assigned codes. After interacting with each woman’s story, the researcher wrote a tentative summary of the woman’s story.

Because nodes were created as the researcher read the text of each woman’s story, a third reading was completed to assure consistency in the text assigned to identified nodes. During the third reading the researcher used the hermeneutic process to move between the parts of the text, reading and re-reading to assure consistency with previous coding. Color coding each node, a feature of NVivo 8, made it possible for the researcher to verify coding and compare coding between different texts. At the end of this reading, the researcher wrote her understanding of the text recorded to each node. Because the full interviews were coded and different nodes were developed as the texts were read, a total of 48 nodes were initially identified. With this third reading, the researcher realized that a few of the nodes were redundant or were addressing a larger topic. For example, *parents*, *siblings*, *significant others* and *other family* were changed to a tree node with the free nodes as subgroups. At the end of this reading the researcher had delineated three tree nodes and 37 free nodes.

True to the hermeneutic process delineated by Alligood and Fawcett (1999) the researcher again read the text coded to each node but concerned herself with specifically and exclusively identifying nodes that addressed the research question. After the text to each node was read, the researcher recorded any new understanding gained. At the end of this fourth reading, text coded to nodes that did not address the research question was separated from the text that did address the question. Text associated with nine free nodes was removed from the study.

With a fifth reading nodes were re-grouped as the researcher's understanding deepened. As the researcher re-read the text with the research question before her, a synthesis of the women's experiences appeared and text assigned to different nodes became clearer. With this fifth reading, the researcher reflected on commonalities between nodes and began to realize that survival occurs in the two worlds-the personal and communal. The researcher then re-read the text to determine if all text could be assigned to one of the two broad nodes, known as parent nodes. As she read, she realized that all the text could be assigned to one of these two broad, parent nodes. This coding, assigning to one or the other parent nodes was completed as part of the fifth reading.

Again returning to reading the text, this time reading all text codes to each of the two parent nodes, the researcher began to realize that not only did the stories tell of experiences in the two worlds, but that survival also moved in a sequential timeframe. As the women told of survival, they clearly noted that survival included moving in time, from one phase to the next. To understand the relationship between world and time, the researcher used NVivo 8 to create matrix between the text code to one of the two parent nodes and to free nodes that indicate a sequence of time. For example, one matrix of personal and diagnosis of breast cancer, allow all text coded to these two were examined. As different matrix were created and reviewed, the researcher clearly recognized that there were three separate phases and that each of these occurred in both personal and communal worlds. Since understanding continuously expands, this process continues until there was harmony between the whole and its parts. A re-reading of the stories as a whole with the visual of color coding seemed to shout "This is what I have been trying to tell you all along!"

In philosophical hermeneutics the researcher serves as interpreter. As such, the researcher faced several challenges. One challenge a researcher (interpreter) must overcome is the phenomenon of strangeness which could inhibit ability to transfer it to the familiar (Alligood & Fawcett, 1999; Fleming, Gaidys & Robb, 2003; Maggs-Rapport, 2001). The researcher (interpreter) in this study is a Lumbee nurse who was raised in and continues to work in the

Lumbee community. She is a contemporary of many of the women who participated in the study. Though she rarely uses the Lumbee dialect in conversation, she understands the dialect, including words and phrases used by the women to relate their experiences. This awareness of the culture, language and communications patterns was consciously used to aid the researcher in understanding the historical experiences of the Lumbee women.

A second challenge for the researcher is to remain open to the text and to interpret the text in such a way as not to distort, decontextualize, trivialize or sentimentalize (Benner, 1999; Darbyshire, Diekelmann, Diekelmann, 1999, Fleming, Gaidys & Robb, 2003; Maggs-Rapport, 2001). The researcher accomplished this by writing her initial understanding in a folder created in NVivo8. In her initial understanding, the researcher anticipated that a) most women would rely on religion or spirituality; b) would have support from their family and community; and, c) would have limited questions of the health care provider. However, as the researcher dwelled with the text, she realized that she had limited understanding of the role of others in a woman's survival story. The researcher made notes as the text provoked ideas and questions and returned to the texts for answers. She moved between the texts taken as a whole back to the parts, reviewed information coded to specific nodes and wrote her understandings frequently. In addition, she interacted frequently with her dissertation chair, commenting on changes in her understanding, surprises in the stories and questions yet to be answered.

CHAPTER 4: FINDINGS

Using the philosophical hermeneutic method the first person accounts of sixteen Lumbee breast cancer survivors were analyzed by a practicing Lumbee nurse to reveal their experiences of survival. The stories of survival, though they share certain features, are very personal. The stories of survival, though very personal, share certain features. Each story documented a path through struggles and changes as the woman confronted breast cancer, survived treatment and created a new life that incorporated these experiences into a new self. The experiences they shared began with the diagnosis and continued the day of the interview, regardless of the time since diagnosis and treatment. These stories, rich in detail about their lives, were freely shared, often with the expressed hope that the stories would be helpful to others. Two women best expressed the value they placed on telling their stories.

Joyce *We do have a bond, 'cause we all each have a story to tell. But it was basically the same, but not the same, 'cause I can say something that might would help somebody else. They could hear it from me but then they might not catch it from the other lady.*

Nettie *Oh, YEAH. I got a lifetime story to tell.*

As the stories unfolded, the researcher recognized that the women were telling of experiences in two worlds: a personal world of self and a communal world with those outside themselves. The reciprocal relationship between the women's personal and communal worlds is such that one could not exist without the other. The experiences in these worlds are interlaced, often within the same paragraph, making it clear that for the women, these are not distinctly different stories, but one story.

Secondly, the stories revealed the process of survival was composed of three separate phases: *encountering breast cancer, moving through and moving on anew*. On further reflection, the researcher realized that the same three phases occurred in both personal and communal

worlds. Finally, dwelling with the stories, the researcher identified different patterns in the two worlds at each of the three phases. In this chapter, the experiences in both these worlds as they occurred in the three phases and the patterns within the phases are presented and supported with verbatim quotes from the women. For the purpose of presenting the findings of this study the two worlds, the phases and the patterns found in each phase are presented separately. The quotes provided are only exemplars of the women's words. Additional examples are available in Appendix B. A visual representation of the findings is presented in Figure 1.

Personal World

The stories reveal the women's experiences beginning with their initial suspicion that they might have breast cancer. The three phases in the personal world were determined to be a) encountering breast cancer, b) moving through, and, c) moving on anew as illustrated in Figure 1.

When initially diagnosed with breast cancer, the women experienced myriad emotions and concerns as they came into the full awareness of the diagnosis. The women were clear that these were internal emotions, ones that they had to face in order to move forward. With vivid detail, many reported a disruption of self, losing a sense of time and place. They spoke of making the decisions or participating in the decisions about treatment. Two patterns were revealed in the women's personal world in this initial phase, disruption of self and disbelief, and decisions about treatment.

Disruption of self and disbelief. Regardless of the time since the diagnosis of breast cancer, women told of the emotions they experienced upon encountering the diagnosis. Several women, more than ten years later, related a keen sense of despair and fear. Their thoughts and emotions range from denial, fear, experiencing a surreal sense of time, and immediate feeling of loss. Fear was a prevailing reaction. One would expect fear of the unknown, but many of the women spoke of their fear about their own response to the difficulties that lay head of them. In the Lumbee community the diagnosis still has a sense of impending death, and many heard a death sentence.

Cathy: *When they told me, my nerves went. They were shot. .. It killed me. Because just the thought of losing my breast at twenty-five years old was—I couldn't imagine it.... I*

couldn't. You know, I worried. And it was, it was challenge... And being—I was afraid. I was afraid of what I would go through. Not of dying, because that's part of life. It's going to come sooner or later.

Joyce: *[After being told over the telephone]. And when he told me, I thought my world had come to a end. I broke down and I cried. And he waited until I got myself together, I guess it was about ten minutes.*

Lucy: *You know when you always hear "cancer," what you think of: you think of death. (Laughs, snaps) And I was just – Lord! I don't remember, because that's when she told me it was cancerous, then. So I really don't remember what she said or anything.*

Ten of the women found the breast mass themselves. Even so, some of these women did not immediately seek treatment because their experience did not match their previous understanding of breast cancer. More than half the women discussed the lack of family history. And several were confused because the mass presented as something other than a "painless lump."

Brenda: *And then of course in a little while I would think to myself, "I ain't got no cancer," and I could go to the Lord about it and everything. And so when I come home, he told me, whenever I thought about it--but I needed to go ahead and think about it--to call him and let him know.*

Ethel: *It was just like it would be a-hurting, the place in my breast. It would hurt, and you could feel the lump. Yeah, I fount (found) the lump myself. And hit (it) had been there for a while before I'd ever done anythink (anything) about it, because, like you said, we didn't know a whole lot about that.*

Maria: *They said it was some type of a cancer, but they—and I don't believe it. I still don't believe it. Went down there, give me a date to go down there, and I went down there then and they took my breast off. And I ain't been bothered with it since. No, I just went ahead like he told me to, and—but I wish I hadn't. I believe it would have cured up after I left that plant. I believe it would quit inflaming. Because none of my*

people ain't had no cancer.

Decision about treatment. Most women relied upon the physician for information about treatment, asking few questions. Some read or talked to others, but it seems that women mainly accepted the treatment decisions made for them. Again fear is a strong emotion surrounding treatment options.

Fannie: *[I was] Frightened, scared, didn't know really what to expect. But he let me, he told me the best way to do, the best thing to do was to have surgery. He said I could either take radiation and see if that would do it, but he said the majority of the time they have to end up having surgery.*

Mary: *I talked to my doctor, mostly. You know what to do. 'Cause none of my family had had breast cancer. None of them had had breast cancer yet, at that-- Well, there not any of them had breast cancer yet, so far.*

Nettie: *Thank God I didn't have to take the chemotherapy. I see people that did take it, that go through the sickness, and their hair coming out, maybe. And I'm just thanking God that I didn't have this to face. I mean, I can relate to people by going just through part of the situation. I mean, I count myself lucky that I just had to take medicine for five long years.*

Three of the women mentioned the "rush to" treatment pressed upon them by the physician or health care team. These women expressed a need for time to adjust to the diagnosis and to reflect upon the meaning for them.

Pauline: *Well, they called and made a 'pointment for me to see the surgeon, to talk to him about it. And that's when he told me he had to do surgery as soon as possible, because he didn't know if it was the spreading kind or not, because of the size it was. So it was—I had asked him to wait a couple days--but see, it kind of throwed me at first, so I told him I had to try to deal with it at first before I decide to do surgery, because it kind of throwed me. I waited a couple days and then called the doctor (laughs) so he could make a 'pointment for me to do*

surger...

Researcher's understanding. As the women encountered the diagnosis they experienced intense emotions. For some, the emotions were so intense, they lost awareness of surroundings, time, and even their own being (fainting, hysterical). The women vacillated between denial and fear. Some denied or questioned the diagnosis because their situation did not mirror their understanding of cancer especially the characteristics of the cancer. In the Lumbee community, cancer is still viewed as a death notice, and they immediately focused on the possibility of their impending death. The women not only feared death, but also disfigurement and the treatments for breast cancer. For most, this is not a time to be active participants in the decision making process about treatment. Only two reported reading the literature offered; only one requested a second opinion. Most followed the health care professional's advice, while at the same time hoping to avoid what they had previously decided was the worst treatment.

Moving through

These women tell of the experiences of moving through, defined as the time of treatment, recovery from treatment and adjusting to a new body image. Transitioning to this phase began with the decision to move on. Interestingly, most women had begun treatment before they reported making the decision to fight the disease and live. In so doing, women chose to focus on living, not on the disease. Strategies for moving through include the patterns of a) deciding to move on with a positive attitude, b) faith: the basis for moving through, c) remaining active, d) not claiming, and, e) dealing with disfigurement.

Deciding to move on with a positive attitude. Fifteen of the sixteen women emphasized their decision to move on. This was not a decision they made just once, but over and over. From the emphasis given to this decision, it was interpreted as a key to survival. This decision to move on was usually accompanied by the decision to think positive and to avoid negative thinking.

Joyce: *I think it was just like a storm that we just had to go through. We had to wade through it.*

Laura: *And it's just something you learn how to deal with. You just learn how to move on.*

I don't let that be a negative. I just take all that, the things that are negatives, that maybe that I have to change, and move, and say, "Well, I'm going to make it positive. I'm not going to dwell on that. I've got to take the rest of my life and make positive, and not dwell on the past." I really try not to think about it. I just try to look to the future.

Lucy: *I can't worry, because a lot of times you worry and worry, that brings you down worse. So, no, you have to be positive for yourself, not negative.*

Faith: The basis for moving through. Faith in God was critical for all 16 of these women. They agreed that their faith in God provided them with the reasons and ways to survive. They believed in prayer, reading the scripture, attending special religious services as powerful means to survival.

Cora: *Because I know I couldn't-a took it like I did if it hadn't had been faith. Ain't no way. Well, if you're not got faith, you can expect anything, where, if you have, you've got enough of faith, you can drive it out.*

Jane: *I was anointed several times during my sickness, and I am a firm believer that I was healed. In the Bible it speaks of calling the elders when there's sickness, and laying hands and anointing... I don't now the number of times that I was prayed for, anointed, but I know that it works. I know that prayer – my name must have been called every day by somebody, because I never had any pain...*

Lucy: *If it was not for the Lord (voice trembles), I don't think I would be here. You know, I guess one thing is what we put into it is what we receive. If you don't put nothing in or towards the Spirit, for the Lord, you won't receive nothing. Is that – understanding what I'm saying?*

Millicent: *I'm going to tell you the most important thing during my life with the cancer was I had angels sing to me. That was a wonderful. Angels. Angels. I had never experienced it. I had read about it, I had been told about it, but I was in bed getting*

ready for Duke the next morning, and what woke me up around 4:00, when I looked at the clock, was angels singing, "It'll be all right when eternity rolls." I will never forget that song. I had never heard it before, and I have never heard it since those angels.

Remaining active . Women shared tales of the value of continuing to be active even during treatment. They spoke of continuing to work, engaging in physical activities or doing for others. Only three women spoke of engaging in any special activities related to treatment such as eating special foods or taking vitamins. These same three women had reported reading about breast cancer as part of the process of educating themselves about breast cancer.

Cora: *I'm just glad I'm able to do. Because I cook for my daughter and them just about every day... Because you're going to be sick sometime. ...I quilt by myself. I put my, roll mine on the bed, and put it on a table, because I can't quilt with the frame, holding my arm up, since my operation. So I just lay it on the table.*

Jane: *I have always taken vitamins, and my mother-in-law, she does a lot of natural things, vitamins and herbs and things. And I was taking Vitamin E, and just some women-things, natural-type stuff. And I had to stop the Vitamin E because it would interfere with the actual surgery, the healing process. But I can never take a hormone.*

Laura: *Ah, I was able to exercise, and go to the fitness center there in Pembroke and work out.. Nothing that I would be exhausted, but in the last couple weeks I was not able to do that, because I really was too weak to exercise. And I just tried to eat – you know, I had a brochure that told me exactly what they wanted to drink, and the foods I should eat. And basically I stuck with that. I stuck with – I did a lot of painting. Something to pass my afternoon away...Always. I love flowers. It's therapeutic, is to work in the garden, and you plant stuff and see it grow, turn into flowers. I love flowers. I like planting flowers and seeing them grow and bloom and all that stuff. So I spend a lot of quality time when I leave here, out in the yard.*

Not claiming. In the Lumbee community there is a concept known as “not claiming”. A concept different from denial, not claiming it is used when the speaker is referring to an event that is harmful or potentially harmful such as an illness. The use indicates that the speaker will not allow an event to define them or take over who they are. This idea was expressed by about half the group across the educational spectrum.

Brenda: *Even though I looked at that doctor in his face and I told him that I weren't going to accept it, and I've never accepted it being a cancer. But I had to take his word, you know, 'cause after all he did stick a needle in me and sent it to the lab. And I had to take his word for it. But as far as me coming in and undoing what I had said, I didn't do and I ain't done it unto this day, since 1993.*

Ethel: *I don't-- I guess the Lord was dealing with me, or something He had to do. I just didn't—I didn't believed it. I just-- I didn't—didn't believe it was there..I believe the spirit of the Lord was on me. I mean, you know, you know how it works, in my mind, that I didn't believe that's what it was. And I never had no problems, from that day to this one, with it.*

Millicent: *I've always said that cancer was “pronounced upon me,” because I never did accept having cancer. I would never say, “I have cancer.” I would always say, “I was told” – if you notice in my sentence, I would say, “The doctors told me that I had cancer.” “They told me that I had three tumors as big as an egg,” or “as big as a lemon.” But I never claimed cancer, no. I never did claim cancer.*

Dealing with disfigurement . Most of the women spoke with intense emotions about the disfigurement that resulted from the therapeutic régimes used to treat breast cancer. Disfigurement concerns included the loss of a breast, loss of hair as a result of chemotherapy and, for those who received radiation therapy, burns and markings. Only two women selected to have reconstructive surgery.

Fannie : *That was a totally different experience. (Pause) I mean, it's something that you don't, I mean, that you can't hardly describe after looking at what you've been through with. It just takes a toll on you, too. You realize, you know, that after everything's over with, and how you come out of it, that it was for the best.*

Joyce :*[M]y breast was going to turn, it really didn't hit me until after I seen it, because it looked like I had two different body parts, colors...Yeah, it turned real, real, crusty, black looking. And that was a shock...I was wondering if it would ever get back right. But it did. It took time, but it did... It's like cooking a piece of meat and burning it up*

Pauline: *.... I don't know, I felt like my life was over with or something, you know, part of my body being taken off. That was hard to deal with...I lost all my hair. I—kind of—felt funny at first. I really was shamed to let my husband and my son sees me, my head was bald. (Laughs) Ah, it felt strange, you know, because you know how you can't find a wig that you really like. But I just dealt with it, even though I didn't really like it. But it's something you had to deal with. It was kind of hard to deal with, you know. Especially after just having my breast taken off.*

Researcher's understanding of moving through. From interacting with the texts of these women's stories, the researcher's understanding widened by grasping the physical and emotional struggles the women endured and moved through. After the initial shock of the diagnosis of breast cancer, women entered the stage of moving through treatment and recovering from the treatment. This phase of survival began with making the decision to fight breast cancer. They told of their decisions to fight and the value of a positive attitude as one began to move through this phase. All of the women spoke about the role of faith as a, if not the, primary reason they were able to move through treatment and its effects. Some women engaged in meaningful activities such as gardening, working, physical activity, and reading. However, all was not positive. They willingly shared the pain of disfigurement and the suffering from cancer treatment. Disfigurement, even temporary, is an emotional, long lasting memory for the women. Many coped with it by placing the

discussion of disfigurement in the context that they were grateful for life; their memories and emotions of disfigurement indicate its significance for them. The same is true of the suffering related to treatment. Some women even expressed that they could suffer through one type of treatment because they took comfort in the fact they did not have to endure the suffering often associated with another. It seemed that the women could look on the bright side of the treatment selected. For example, women who received chemotherapy noted that that at least they did not have to deal with radiation. The reverse was true for women who received radiation and not chemotherapy.

Moving on anew

For these women the experience of surviving breast cancer has been a transforming experience. Each is a new person with a new inner strength and new roles in life. In this final phase in the women's personal worlds they described the patterns of: a) a transformed self, b) caring for self, c) disfigurement-still, and d) reoccurrence.

A transformed self. All the women told of a personal transformation that resulted from surviving breast cancer. They spoke of overcoming fears, becoming more grateful for life, developing a deeper relationship with their god and with others.

Ethel: *And I used to, used to, before I got the cancer, I feared—I had a fear that I was going to get cancer. You know, after my dad died, I had a fear that I was going to have cancer. But after I got cancer and had surgery and all, that fear left me. I didn't have it anymore. I don't have that fear no more... I guess it brought me closter (closer) to the Lord. That was probably the benefit, yeah. It made me get closter to God.*

Fannie: *It's helped me to become a better person. It helps you to realize from day to day we don't take it for granted. It's not something that's give to us, and we have to work for it. Have to trust in the Lord, depend on him, because that's where our faith comes from, to believe in. I, at one time I felt like I, it was a let-down, or a disappointment, but then I looked back in terms of going back to the Lord. I said, "Things like this comes upon us. We're no better than nobody else."...*

Nettie: *Well, I can't say I really lost nothing. I really gained a new experience for life, you know. You take life so for granted, and then when you go through something, at least you have a better outlook on life. You say, well, "I've been through the roughest spot, and I survived." And I am -- you're looking at a survivor.*

Pauline: *Uh, hit [it] made me stronger. And knowing how to deal with sickness a little better. I think a lot of times the Lord lets us know, you know, by being sick, seeing what we have to go through with the—bringing to the church. But I think He sees how much you can deal with.*

Caring for self. As a breast cancer survivor, these women reported a need to care for themselves. All spoke of continuing follow up appointments and mammograms. Some spoke specifically of watching their diet, including special antioxidant foods, and exercise.

Cathy: *I exercise a lot. I walk to try to stay healthy, and I watch what I eat, and I don't take that shot anymore [speaking of Depro].*

Cora: [In response to a question about follow up after completing treatment.] *Oncte (once) a year. Sure have. And I go to -- I don't know her right name -- my cancer specialist, oncte (once) a year.*

Mary: *I get out and walk every morning. I was a-going to the track out at college, but this morning I went and it was closed, so I just walked around the college. I've been a-doing it ever since, um, sometime in January. I started in January. But mornings that it rains, I don't get out....*

Jane: *And I think if there was some way of going back to natural eating, preparing meals instead of prepared, box dinners and those kinds of things, we'd be a lot healthier. I do take extra vitamins. I do not take anything that I feel like would damage my body, and I'm very, very aware of what I cannot take since I've gone through surgery and treatment. I do take a natural herb -- Vitamin E, and black kohosh, which is a Native American herb.*

Disfigurement – Still. Surprisingly, 15 of the 16 women mentioned disfigurement related to treatment. Time does not appear to be a healer. For these women, a disfigured self is part of who they now are.

Laura: *So it really, it's a, you just have to learn how. I guess the biggest thing is learning how to change your life. From one second you're a whole person, to the next second, you might be, you know, losing a breast or having scars the rest of your life, or maybe having to take medications would leave you like – like my, I have problems with my – hmm – ribcage has been sore, and that's because of the radiation. There's certain bras I can wear and certain I can't. And it's just something you learn how to deal with. You just learn how to change.*

Lucy *The surgery, the tubes being tied –That was my roughest. Because I had to have chemo, they didn't want me to get pregnant during chemo. See, and then they took that muscle here, from my stomach, and made me a breast.*

Maria: *Here lately, I reckon I just—I reckon it just worries me to think that I didn't have sense enough to know I got a, one, a breast, but it was too big. It's way bigger than the other one, my other breast. So I got it back yonder. I can't wear it. And the place down here at Lumberton, a girl had told me. But I don't know where it's at. I wish I did. If I did, I would go down there and get one. If you ain't, you're going to have—it'll worry you bad that you can't go where you want to go without having something or another to hold the other side straight.*

Reoccurrence. Three women were dealing with reoccurrences. Interestingly, fewer than half of the other women mentioned reoccurrence and it was mentioned by women who had survived more than ten years.

Laura: *... after I got through with my treatments, I, you know, started with Vitamin C, Vitamin E, and D, Evening Primrose, and Flaxoil Seed. So, I'd use – and all those*

were natural – so I'd take all that, and –...Especially after you do your reading on Flaxseed Oil. If I was to have another one, it would shrink it. I've read where there were –for the time they get ready to operate it'd be a size smaller. So I live on that. I eat a lot of berries, blueberries, strawberries. Anything that fights cancer.

Millicent: *I got to get the CAT scan, the chest x-ray, I got to get the mammogram, and you know, I mentioned the bone scan. I'm sort of out of it. But then when I get my results, I'm happy again. But I become despondent when I'm on my way to Duke.*

Pauline: *Oh, like I said, it made me stronger. Because I had to deal with a lot, and I think I got it all under control so far, if it don't come back. I just hope it don't come back. But I might could deal with it even better, though, if it comes back. Hopefully it won't.*

Researcher's understanding of moving on anew. According to their stories, the experiences related to surviving breast cancer continue indefinitely. Surviving breast cancer is a life transforming experience that often brings one closer to her god and a renewed appreciation of life. All but one woman was continuing to follow-up with a health care provider; they still faced these visits with anxiety. Though most acknowledged that they continued to receive mammograms and complete self-breast examinations, few women offered to comment on these. However, they did discuss other self-help activities such as exercise, taking vitamins and eating more fruits and vegetables. Most women spoke, some even after years of survival, of the disfigurement they still experience as breast cancer survivors. They bemoaned the loss of a breast, dealt with ill fitting prosthetics, selected clothing based on scars and disfigurement and felt uncomfortable even with their spouse. They continue to consider the possibility of reoccurrence, reporting being despondent or anxious about follow up visits and taking steps to prevent reoccurrence.

Understanding the personal world

In an internal world of self, the women moved through three different phases of surviving breast cancer. These phases were identified in all the women's stories regardless of the length

of time from diagnosis to interview. In the first phase, *Encountering breast cancer*, they described the intense assault on their person as they had a sense of loss of self. Before the women adjusted to this change in person, they had to make decisions related to treatment. Though they listened to the options presented, most trusted the recommendations of the health care provider so that treatment could begin. They chose a treatment that would allow them to cope with this abrupt change in their life, with their own mortality and with the loss to their families by their potential death. They participated in the decision making by making the decision that only they could make and left the clinical decisions to those prepared to make clinical decision, trusting in their faith that everything is as it should be.

The second phase, *Moving On*, was focused upon surviving and adjusting to treatment. The women reported that it was during this time that they made a decision to fight cancer to continue to live. It was as if they awoke from the abyss of the destruction of personhood to find themselves dealing with treatment and the need to regain control of their lives. Faith was the primary source of personal strength. In addition to their strong spiritual foundation, women told of the importance of a positive attitude, continuing meaningful activities and not allowing the cancer to define them as people.

In *Moving on Anew*, the final phase in the personal world, women described the transformation that occurred as a result of surviving treatment and continuing forward. They described the expansion of themselves as new beings in their personal world. They did not tell Pollyanna stories, but willingly shared their pain, fears and concerns. Often told with emotions for which they apologized, the women's telling of their experiences provided the researcher with a new understanding of the experience of breast cancer, an experience that does not end with the end of treatment, or after surviving for five or even ten years. Amazingly, all the women's stories ended in a message of hope for the future, a firm belief that this experience allowed them the opportunity to change, moving towards a level of high self-actualization.

The Communal World

Through their stories, these Lumbee women who are breast cancer survivors reveal experiences that have significance and meaning only if understood as communal. While they told of the reality and meaning of some experiences for them personally, at the same time, they told of their experiences as clearly imbedded in their families and communities. The experience in their personal world and the experiences in their communal world can only be understood in light of the other; they coincide. Figure 1 provides a visual representation of the three phases in the communal world as well as the patterns discovered in each of phase.

Each woman shared stories of the significance of family, friends or community to her personal world. Sometimes the stories described how interactions with people changed the woman and provided her with strength to progress from encountering breast cancer, to move through treatment and related complications into the final phases of becoming anew. In other stories, the woman tells of how she provided strength for family and community members to move through the same phases. Most often the women spoke of both in the same paragraphs, demonstrating the interrelatedness of the worlds. The same three phases of surviving were found in both worlds, usually occurring simultaneously. Though the phases were the same, there were differences in the patterns within the phases in the communal world as compared with the personal world. The following is a discussion of these three phases and the patterns delineated within each in the women's communal world.

Encountering breast cancer

From the initial finding of a lump, breast change or abnormal mammogram, the women included others in their story. Thus, experiences in the communal world closely followed those in the personal world. Women shared with others the finding of the mass, the abnormal mammogram, and the experience of diagnosis. Several women depended on family members to decide on treatment options. Several of the women made an appointment with a health care provider only after a family member encouraged them to do so. Most of the women were with a family member when they were told that the tests were positive for breast cancer.

Ethel: *No, I didn't try nothing else. I really didn't even tell nobody about it. And one day at work it was hurting, and my first cousin, I told her, and she said, "You need to go do something about that." So that's when I went to the doctor.*

Jane: *After I saw, went to the doctor for my follow-up, within a day or two the results was back, and I had the biopsy, and then called, come in for a conference, my husband and I, and verified that it was cancer.*

In the first phase in the communal world, *encountering breast cancer*, four patterns were discerned: a) *not of our people*, b) *shared fear, shock and grief*, c) *not something to face alone*, and, d) *deciding on treatment*.

Not of our people In their stories the women frequently repeated their own and their family members' response as wondering where the cancer originated. This same dialog occurred between mother and daughters, sisters and extended family members. The women in their stories emphasized that their people did not know this disease; and thus it was foreign to them. For the families and communities that had experienced breast cancer, they used these stories as guides to coping and decision making.

Brenda : *But anyway, no, we hadn't heard of any cancer until my sister's daughter came up with it. 'Cause Mamma said she hadn't knowed a thing in the world, but it outdone her, you know, because when she found out that the child had cancer--well, whenever my sister, when the doctor found it, she said she didn't know where in the world it could have come from. There weren't none of my family, all the way back to my great-grandfather, she said they never won't.*

Mary: *'Cause none of my family had had breast cancer. None of them had had breast cancer yet, at that--*

Pauline: *But we couldn't think of nothing but just when we used to farm, you know, we been around a lot of that chemicals, you know. And back then it didn't bother us, you know. (Laughs) Didn't realize it, but it could be something else. It kind of bothered us, not knowing where it come from.*

One woman added the importance of her mother's acceptance of the diagnosis. This was the not the same as not claiming nor denial. The mother did not believe even after the daughter had surgery.

Maria: Yeah. She would say, "Mary, you ain't got no cancer!" I'd say, "Well Mama, that's what they operated on." She'd say, "I don't care. You didn't never have no cancer." She told me that every time. And I believe her. I ain't never been bothered with it since. I weren't bothered with it then, just a little sore come on my breast.

Shared fear, shock and grief. As in the personal worlds, the women's communal world experienced an upheaval even when breast cancer was suspected or confirmed. This was shared among different family members and tribal members at large. In reflecting on this, some women were overcome with emotion, from crying to nervous laughter.

Dorcus: *Very scareful. Very, very scared. In '87, when you found out you had cancer, you thought, "death." Everybody thought, "Death." You're going to die. My husband wouldn't even talk about it. He wouldn't even talk about it. About six months later he tells me, "You know, I thought you was going to die and leave me," you know. But you know, "You're going to die." You know, "Death." That's the first thing they think about. But—Um, scared. Scared. But my oldest son, I tell people he's my Sampson. He's tough. I mean, he has to set me straight sometime, you know. (Laughs) He's tough. He'll say, "Mommy, you'll be alright." You know, "It'll work out fine." C_____ is a little more sensitive, second-oldest one. They cried when I weren't looking. They were scared. Everybody was scared.*

Martha: *Well they was hurt. They was real down. But they told me, "You're strong, you can do it." And I did. Some of them – a couple of sisters, they took it hard. But that was understandable. Well, and my family too. My husband, you know, he started – he would break down, but he was there for me. The children, they were still in elementary school and high school then, at that time.*

Millicent: *Well, my kids went into shock. They went into shock. They went in shock, and my husband went in shock. And myself, I think I—you know, I had the crying spells, and he would pray for me, and I would do better, and do better, better, better, better, and then I would have the crying spells, and do that again, crying spells, better again. But it does affect a whole family. It just didn't affect me. I think it affects the spouse more than the person that has the cancer. Because it affected my husband more than it did me, when I was told that I had cancer.*

Not something to face alone. Women who were alone when they were told the diagnosis quickly sought comfort from others. Some women noted that they had limited memory until they were able to tell others. They shared the news with significant others, family, and community members.

Dorcus: *And my family, my family was already being very supportive. And they'd get ganged up together to go with me to get my mammogram, to get the biopsy, the surgery. They're all—I mean, a room full of people. Everybody's there, children, husband, sisters, brothers. Everybody's there.*

Laura: *When he came in I was crying. And I said, I told him I got the results back, and I told him what had happened. So he started crying. So it was really very, very sad. And then we called our preacher, which is B J L. He prayed with me. (Pause) And he said God will take care of me. (Crying; pause in recording) Going back to it, it just makes such sad, sad feelings. Aw. Oh. My children were just horrified. My son was in Canada. He was in school. We didn't tell him until he returned back, because I knew he had to pass a test.. So, my daughter was very concerned, and my husband and my sisters. My sister-in-law, my entire family was there to support me. It was a daily visit, and a daily to make sure I was alright, or what can they do.*

Lucy: *We all – we're out there together, you know, and everything. Because the night that I found out that I had cancer, I had come, went by my mama's house – mama was with*

me when I found out I had it. And I went by my sister's, my twin sister's, house, and I told her. And then I don't know if I – I can't remember –

Deciding on treatment. Women depended on family members to help make the decisions about treatment. Though they noted that the final decisions were theirs, family members were included in the decision making process, often expressing concern about the decisions the women made.

Brenda: *So I told my daughter what was going on, I said, "And he wants to talk to both of us." So we went back up there to his office and called him, of course, and made a date with him. Went up there and talked with him, and he explained to her how, you know, he could do--he could just go and cut across like this and take it out, 'cause it was just a little thing. And so when she agreed with it, I did too. I told her one day, I said, "I don't know what I would do without you, girl. I sure wouldn't.*

Cora: *'Cause he talked to me, and then I told him I'd like for my daughter to talk to him. He called her at work and talked to her about it.*

Lucy : *[Speaking of her mother's thoughts about breast reconstruction] My mama didn't want me to go through the surgery. She just wanted me to have it removed. I said, "Mama" – I was young! And it was just too big, they couldn't do radiation. And so where it was positioned at, they said it was best that I go ahead and have a mastectomy, because it was in my milk gland ducts, or whatever. [And your mother said no?] No, she didn't want me to go through it. But I said, "Mama, I'm young! I'm thirty-three years old. I'm still young!" [So she didn't think you needed the reconstruction?] She just didn't want me to go through it.*

Millicent: *He wanted to do surgery immediately, and I said no, and my two daughters said no. They said, "We'll be back in ten minutes." I said, "No, give us twenty-five minutes. We need to pray first before you come back." And they allowed us to be alone thirty minutes to pray, my husband and I. And we said we wanted a second opinion ourselves. He did not recommend a second opinion. He was going to do surgery immediately, and we said we wanted to go to Duke.*

Researcher's understanding. For the family and the women being diagnosed with breast cancer is an emotionally intense experience. For these women, the experience was too heavy to carry alone requiring that they share the burden of this disease with others. Through the details they provided about the shared experience, the researcher understood the importance of sharing this with others. The communal experience was within families including parents, significant others, siblings, children (even young children), church and community members. Within the community the question arose, "Where did this disease come from?" For women whose historical context included being in community with another cancer survivor, they used the stories of other to help them cope and to make decisions.

Moving through

The women's stories were such that one re-lived the experiences with them in their telling. This was facilitated by the women's use of first person plural pronouns. The experiences in the personal world were reciprocal with those in the communal world, supporting and assisting her to move through the breast cancer treatments by deciding to fight for survival and continued through their experiences of treatment and its aftermath. The patterns in this phase within the communal world include: a) *knowing through communal suffering*, b) *the faith of others*, c) *depending on others*, and d) *concern for others*.

Knowing through communal suffering. All of the women depended on their understanding of others' stories to provide them with information and a path to follow. In the interviews they gave voice to the stories of others who had suffered with cancer. They relied upon the stories of other breast cancer survivors, community members who had suffered from other types of cancer and the family members of those who have had cancer. But all the stories were the stories of people who had survived longer than they, as well, even if the people later lost the battle with cancer.

Brenda: *Well, naturally I thought about my sisters and my niece, 'cause I had to stick with them. I'd go to Duke's with that girl 'bout every time she'd go up there, I'd go with her, and that's what popped in my mind, you know, because they were the only ones in the family been through with that And so I--that's as far as knowing anything about how anybody suffering through the cancer. That's how mine first started, and come about through my niece and then my sister.*

Maria: *[My daughter] had a youngun, and whenever the youngun was born, they thought she was going to have twins, but when the youngun was born they found out it was a tumor in her. And so they took and operated on her, and it was a cancer. They said it was malignant. And when they was taking it out of her it busted in her. And she lived about a year after that. And I took her back home with me and kept her and the baby, until the Lord took her home. And so now I've got the boy with me.*

Martha: *Well, ah, I take it one day at a time, there, and it didn't bother me until it started, you know, my sisters getting sick. It sort of worried me a little bit. I said, "Well, it seemed like when I get sick, and now it's starting, going down the line." And it's sort of gets the best of you for a little bit. But I just keep looking up...Well, after I found out, you know, I had it, I just wanted to find out more about it, and the approach and everything about it. But I think I done pretty good, by people talking.*

Millicent: *I had several cancer patients visit me. I would say approximately eight or ten, and Miss B____ B____ was one of those, a woman whom I admired, who fought hard to live. And I knew she would not mind me calling her name. She would call me and give me advice. She told me so many times that I had to fight, I had to have faith, I had to believe, that we could beat cancer, we could beat it. She said, "We're going to beat cancer." And I said, "Of course we are, we're going to beat it." And we fought together, and we fought and we cried together, and we shared*

our testimonies together. And when B passed away I'd sort of given up. I started giving up. And then L F, who was B's friend and my friend, then I began to get attached to her, and then her cancer then began to spread. And she's still living, fighting, fighting, fighting.

The faith of others. Each woman shared at least one story of how she gained strength to endure from the faith of others. For some women this was a shared faith in the same God. In descriptive detail, they retold of praying, anointing and singings. Others found strength in the faith people had in them.

Jane : *And it was. I don't now the number of times that I was prayed for, anointed, but I know that it works. I know that prayer – my name must have been called every day by somebody, because I never had any pain.*

Joyce: *When I was anointed it was with oil. This man, one of the men at church, they called an altar prayer, and I was standing there and he called me out and he anointed me with oil. And during his praying, seem like I could just feel it going all down my body. And I just felt the spirit, and I just knew that I was going to be alright.*

Martha: *The main thing, because, it won't for that, I don't think I'd be here. Because of the people, and the church. Because the first time when I had cancer, the church people was here supporting the whole time.*

Nettie : *My children was great. "I knew, Mom, that you could do it." You know. They was just like – they was like a comforter, because they had so much confidence in me. And I'm like, "Oh, Lord, I'm here by myself," but the children, they was like giving you a great lift because they had so much faith in you that you could survive and get over it. And I did, with the Lord's help.*

Depending on others. All of the women had to learn to depend on the care of others. For most of the women, this was a struggle because this was a reversal of roles. Family, church and community members reached out to meet their daily needs. In the stories they revealed that this caring was along traditional roles, with women providing different care than the men.

Cathy: *Hmm. Well, the same in return. You know, my mother-in-law—well, she weren't my mother-in-law—but she sat with me. She sat beside me during my whole surgery, even though I weren't awake. When I woke up she was the first face I seen. You know, when they brought me home, she come in every day. She would come in the morning time, check on me to make sure I took my medicine. And even when I was sitting throwing up, couldn't hold my head up, she held it up for me, honey.*

Cora: *I didn't do too much talking to him [speaking of her son]. I just figured it was more of a woman-thing... Well, to me, I go to the daughter, and then if it gets to the sons, it's fine. Which, now, they were there during the operation and all. Well, my sister, she came and stayed with me during the day, because I was living by myself. And my daughter, she'd come by every morning going to work, and dress it, and do what had to be done. [So your sister and your daughter came by. What about arranging your affairs, taking you to doctor's appointments and stuff like that?] My daughter'd usually get off and take me. My daughter-in-law, one of them, would take me. [What about your sons?] No, their wives did that. Mm-hmm. Because now, one son, he'd go get me and my sister breakfast and dinner every day, bring us.*

Ethel: *Ah, they came to the house, and they would help, you know, with my housework, and they would bring food, and prayer. You know, visits. And they gave me money during that time.*

Pauline: *Ah, the support around me. And if I didn't have that I probably would have went downhill. But you know, I think that makes a person better too, by support, having*

a lot of friends. And especially my neighbor, and my family, and my sisters was so supportive of me. They'd come and visit me, and you know, you go through them stages where you get depressed too, you know. Cry a while too. (Laughs)

Concern for others. Even in the midst of their suffering, each of the women shared stories of their concern for those around them. For some, their concern for others was the reason to keep going. All maintained their previous family roles as much as possible.

Brenda: *But there's a lot I've had to do to look out for myself on the account of them granddaughters, in order to keep myself, with the good Lord's help, on the move.*

Dorcus: *Uh. (pause) My baby boy, I didn't—evidently he was born asthmatic. But he had asthma severely. I have had him to stop breathing on me at home. And he started, was having a little bit of wheezing and all this before I had the surgery. And I had the surgery on a Monday. That Tuesday night, my husband and my youngest son, my baby boy, stayed at the hospital, because my son was having difficulty breathing.*

Maria: *All my younguns'd come here and eat dinner on Sundays. They'd come and eat dinner with me on a Sunday. We'd all go to church. All of them go to church, and all of them would then come in and eat dinner.*

Nettie: *I had church friends to come in. It was like we was keeping a lot of it kind of undercover, on account of the children was home then. The boys was home, and we didn't want to get them too blowed away in thinking, you know. We kind of kept it undercover, so we had a few real close friends.*

Researcher's understanding of moving through. Through these experiences the women gained knowledge, strength and purpose from their community. These came in a wide variety of ways and from a wide variety of people. They told not only their own stories, but recalled the stories of others that they used to provide them knowledge, strength and purpose. This is a clear

example of the benefit of listening to stories and that knowledge from within the same historical context was most valued. Women learned to depend on others yet at the same time sought to maintain their own roles in life. Often the care from others and their care for others were along traditional lines. None of the women participated in a cancer support group. They saw cancer support groups as outside their communal knowledge.

Moving on anew

The women are finding purpose for their suffering in their communal lives. Often this involves becoming part of the communal knowledge, being active in family and community activities and providing care for others who are suffering. The women spoke of their struggles with breast cancer as having been for a purpose; usually they saw this purpose as serving others. The three patterns identified in this phase in the communal world are: a) *communal activities*, b) *contributing to communal knowledge*, and, c) *communal caring*.

Communal activities. Seven of the women spoke of their involvement in local community activities. Most of these women told of their many activities in the faith communities, not necessarily their own. Two women talked at length about community or tribal action projects in which they had become involved because of their desire to give back.

Joyce: *If I hear of a gospel singing, I try to go and support the gospel singing as long as it is helping promote the word of God, or through singing or through preaching.*

Cathy: *Mm-hmm, we have our community project we're trying to start right here in Maxton, as a matter of fact, between Red Banks, Prospect, White Oak, Alma, and Evan's Crossroads. You know, the kids around here, they have nothing to do in the summertime, and instead of seeing them sell drugs or do drugs, we're trying to get baseball teams, community services where they can work—people that don't have educations, help them get an education, even if they have to pay them—and get some*

of these people off drugs, and get the drugs out of this area. And make Drowning Creek look like it was when we were kids.. It's made me want to make a difference in my nieces' and nephews' lives, give them a better place to stay, and you know—just environment. I want them to have a better environment than what they're in.

Contributing to communal knowledge. All of the women spoke passionately of contributing to communal knowledge. Most provided stories of how they had helped other women who had breast cancer. Three had organized community efforts to inform other women about breast cancer.

Brenda: *Right now I'm trying to help one of our young sisters that was just operated on about two or three weeks ago now--but her mother told me out there at the church that she had lost both of her breasts, and I didn't even know it, and we've been churching together for over a year now, I reckon.*

Jane: *I feel that God allowed this to happen to me for a reason, and I think a part of that reason is so that I can witness to others, and can be a support group for them. Somebody has to tell the story. And I feel sure that my support group, and what I do, and what I say, to others, is my way of saying, "Thank you, God, for allowing me to stay.*

Laura: *I do. I have spoke on our state-wide North Carolina Electric Cooperatives – I speak, I was at a conference maybe last year, and I shared with them and others that were there too. So, I speak every occasion that I'm asked to speak, I do. Because I feel like people need to know that their life can go on. It's not the end of the world. But also, people need to know they need to have mammograms, because the early detection is going to depend on whether you're going to be a survivor or not.*

Communal caring. Just as all the women were called to add to communal knowledge they all were called to provide some type of care of another. The care was diverse; from cleaning house, cooking, or providing transportation, to providing hair for wigs. But, just visiting was an important contribution that they mentioned.

Lucy: [Speaking of her hair that had returned after chemotherapy] *A couple years ago, it was down to here. I cut twelve inches off of it and donated it to the Cancer Center, I said, because I know how it feels to be without hair. I wanted somebody to make a wig out of it for some child or somebody. I just thank God.*

Mary: *We have to go visit them, ask prayer for them. It is, VERY important, that you pray for one another. Very important. Not only the Indian people, the white people and every race of people that knows that they've been born again, they need prayer. Prayer is the key to Heaven. And other things too, like your neighbors, helping your neighbors. If they're down and need help, go help. Don't turn them aside. Do things to help one another, because we need one another. That's the reason we're here, is to get along together, and to care for one another. That's the way the Lord would want it,*

Pauline: *Yes, I—I've really had some people to contact me, because they found out I had it, and they wanted me to support this lady over here where I used to stay at, because she had breast cancer too. And they took hers off, and she felt so secure under me, you know, when I was talking. You know, when she asked me questions, that's when I can talk, you know. Sometimes! (Laughs) But you know, you just can't remember everything, you know, about something that brings it up. But I told her if she ever needed me, you know. I give her one of my bras too, you know, because she hadn't had a bra.*

Researcher's understanding of moving on anew. With eloquence yet humility, the women told of sharing their 'second chance' with others. They spoke of the renewed purpose of living in community, including providing for future generations. The researcher's understanding of survivorship now includes this sense of a new life- a life of service, of contributing to communal knowledge and helping others who are walking the path of survivorship. Thus, allowing the

community to transform and change as well. The researcher was intrigued that women were interested in reaching others at the group level. Like their experiences of moving through the treatment phase, the women look for new experiences from within their cultural context. They used what they had valued in their own experiences to provide direction for this new life. From their stories it is clear that participating in community survival is not just the re-telling of one's story, but sharing the suffering including the power of one's presence.

Summary of the communal world

Through the stories shared the researcher understands that the process of surviving breast cancer is not accomplished by the person alone, but in community. The process of surviving breast cancer is not one between a dyad of one woman and her health care provider but involves the family and community as an intimate concern. Through communal experiences women sought ways to cope with the disease while maintaining some degree of normalcy. The women described the shock and fear that their family and community members experienced. They discussed the question of "Where did this disease come from?", and looked to their historical context for answers on how to cope and treat the disease. Women depended on others to move with them through the pain and suffering. Extended family and community members provided support that often allowed the woman's family to continue normal patterns of living and follow traditional gender roles. The faith of others holding them up, either because of past experiences or faith in God, provided the women with courage and hope. As a result of being in community, the women, thankful for their second chance with life, moved to becoming more involved with the community as a whole and with other individual women who had breast cancer. They willingly shared this life with their tribal and faith communities. In addition to adding their experiences to the communal wisdom, they described their presence as valuable to the community as a whole.

Summary of Findings

In stories of their experiences of surviving breast cancer, Lumbee women reveal the relationship between personal and communal worlds. This relationship is reciprocal between the

woman and her community such that without the communal there would be no personal and without the personal there would be no communal. They also reveal three phases of progressing from an event that created great distress to becoming transformed to a higher level of purpose and a member of a changed communal environment. The interpretation of their stories further disclosed different patterns within the three phases that occurred in the personal and communal worlds.

The experiences shared by women occurred in two worlds and disclosed three phases in the survival process. The women told of experiences in their personal worlds, ones that influenced their own personhood. The first phase began upon hearing the words “breast cancer”. From within this abyss, the second phase began with the women tell of making the decision to fight breast cancer, of deciding they wanted to live. They found the inner strength and purpose to endure treatment through activities, a positive attitude and their faith. Even when memories brought tears, the women did not hide the pain and suffering they endured as part of this process. Disfigurement from losing a breast, losing their hair or enduring burns from radiation was noted by most of the women. It seemed they were saying, “I can handle anything but this”, but this is what I have, so how do I handle this? Women refused to allow breast cancer to define them, a pattern that appears in many Lumbee conversations as, *not claiming*. In the final phase, the women had undergone a transformation; they were a new person and live in a new community. In this newness, they find purpose in their experiences, share them with others, care for others, and look towards the future. They were appreciative of life yet continued to address problems related to treatment, especially disfigurement, and feared reoccurrence.

Surviving also occurs in the communal world, in community with others, families, elders, friends and community. Again survival is a process consisting of the three phase of: a) *encountering breast cancer*, b) *moving through*, and c) *moving on anew*. In the initial phase, the first pattern was discerned by a question raised by most families-- “where did this disease come from?” The people reflected back to their historical context for wisdom to use to confront this disease. The family and community shared the initial shock and fear, yet also offered critical

strength and support. These came from being present with the women and helping decide on treatment plans. In the second phase, the women shared experiences they had within their community and the community's experiences, as together they moved through breast cancer. Women used communal knowledge of suffering as their guide and communal members used communal knowledge in knowing how to respond. In this second phase, communal living included being present, addressing daily living, and standing with the women in their journeys through shared faith- faith in her and faith in god. In the final phase, the community was transformed as a result of engagement with the women and the women's engagement with the community. Women shared their experiences with the community members to aid each another, joined their voice to the community voice of encouragement and support, and contributed their knowledge to the community knowledge to offer expanded education. The communities were ultimately enriched by their involvement in community concerns.

CHAPTER 5: NEW UNDERSTANDING

The experiences of Lumbee women surviving breast cancer were unknown. This interpretive study launched an understanding of these experiences that had not been addressed in the Lumbee or nursing literature. In this chapter the new understanding is shared, and the findings are discussed from the cultural and nursing context. The chapter concludes with an analysis of the significance for nursing and recommendations for further study.

Conclusions

The experience of surviving breast cancer is a transformative process for both the women and for their community. The women's realities of who they were as people and as members of the community changed. In turn, however, the women's families and communities were also transformed in an interdependent process. The women told their stories of changes within themselves and their community as one experience. From within their cultural context, the women portrayed survival as both a transformation of self and the expression of self within the community. The community was also transformed by the women's experiences, and by the new persons they had become. Now they share their voices as individual voices within the larger communal voice. As a Lumbee nurse, the researcher now understands that survival means these transformative processes of person and community occurring simultaneously.

Transformation for both the women and their communities required working through three phases: a) *encountering breast cancer*, b) *moving through*, and c) *moving on anew*. The repetition of these phases within both worlds further emphasizes the integrality of the two. However, within each phase, different patterns were identified as occurring in two worlds, communal and personal, reflecting the value of each world's role in co-creating meaning to survival. Faith and spirituality, including prayer and presence, were patterns repeated in both worlds and in all three phases.

Prior to this study, the researcher understood the experiences of surviving breast cancer to include a strong connection between family and community, as well as a strong reliance on

faith and religious practices. After this study, understanding now includes: a) the reciprocity of the experiences in the personal and communal worlds, b) the phases of change are a critical part of survival, c) the personal and communal worlds undergo the same three phases but have different patterns that are used to assist in survival, and d) survival is a transformative process for the woman and her community. Now, along with faith and spirituality, the researcher includes presence as a critical pattern in each stage of progression in the world of self and community. Though educated in nursing in a postpositivistic era, the Lumbee nurse researcher innately sensed a deep interconnection between and among humans. She had participated in the Lumbee community with distressed persons encountering life-changing events. She had been present when family and community gathered at the bedside or waited for one to return from surgery. But, even with this background, the researcher had not fully understood the relationship between personal and communal survival. In fact, the researcher was surprised by the intensity of the relationship which was unveiled in the stories of these women. Now, she understands the relationship between the personal and the communal and the phases required to allow one to be transformed as quintessential for healing.

Discussion of the Findings

Understanding the Findings from a cultural context

Though this is the first study of its type in both Lumbee and nursing literature, the researcher's findings are very probable, a requirement for rigor for hermeneutic studies. The scant literature on the Lumbee population provides a nod to this new understanding of survival as dependent upon the integrality and circular movement between the communal world and the personal world. The women of this study did not separate themselves from the other, an interrelationship so intense that often the women shared others' stories as a part of communicating their own stories. The women used phrases such as "taken under the wing" of another as places they found personal strength and meaning, a phenomenon found in most of the literature written about the Lumbees (Blu, 2005, Crenshaw, 2005, Deese, 2003; Maynor, 2003 and 2005, Ransom, 1989). Deese (2003) defines relationships as the central concept in Lumbee

worldview, while Blu (2005) and Maynor (2005) discuss the complex kinship patterns that allowed the Lumbees to survive as a people. Blu, an anthropologist who has studied the Lumbees for 20 years, writes in the *Lumbee Problem* that the intense sense of community is one of the reasons Lumbees have defied anthropological odds and continue to survive as a separate people. Crenshaw and Maynor discussed the communal behavior of communal vocalization, a time when individuals would simultaneously tell stories or sing in an effort to support a primary speaker, one in need of help or each other. Finally, Hudson et al. (1998) (including the researcher for this study) found that in response to an open-ended question about personal experience with abuse, Lumbees provided examples of societal abuse against their people, a finding not explored by the authors.

Given the need for community, the use or lack of use of cancer support groups is surprising but is supported by other Lumbee literature. In this study, women leaned on others for emotional and physical support and found encouragement and knowledge from the stories shared by others. Yet, these women reported that they choose not to participate in cancer support groups, with most noting support from family, elders, friends and clergy as sufficient. A few women did attend a single support group meeting, but experienced sadness instead of support in these settings. The expectation that the communal world would be involved in the process of diagnoses, treatment and healing also reverberates in other health studies (Hudson et al., 1998; Locklear, 1985; Michielutte et al., 1999). Lumbees accessed health services provided by trained health professionals, but they preferred communal services. Locklear (1985) and Michielutte et al. (1999) report the lack of Lumbee participation in interventions as being related to the preferences for community interventions.

Through the ubiquitous role of faith and presence emphasized by the women in this study in not found in other studies, two studies support this finding. In this study, faith, spirituality and prayer were recurrent patterns in both the personal and communal worlds and in all the phases of surviving. Women stressed the number of people who were with them as they encountered and moved through the experiences of breast cancer. In *Going on Anew*, they spoke of their new role

of visiting and being with others dealing with similar experiences. The role of faith, including prayer, is the major finding reported by Crenshaw (2005). He argues that Lumbees place much emphasis on the power of prayer to heal and relieve suffering. Ransom (1989) identified four values used by grandparents to aid a child in the process of becoming a productive tribal member; one of which was akin to presence: sharing of oneself as defined by time and energy. He proposed that such "sharing" was the most powerful value that grandparents practiced to raise a Lumbee child.

Understanding the findings from a nursing context

As the first study of Lumbees in general and more specifically of Lumbee breast cancer survivors, the findings of this study provide critical information about providing nursing care. While no other studies of the Lumbee exist, there are other nursing studies that support the findings of this study.

Nursing studies of American Indian breast cancer survivors. Though nursing had yet to address the Lumbee population, the findings of this study have commonalities with two previous studies of American Indian breast cancer survivors. In this study women described the result of experiences as new, transformed selves and community in *moving on anew*; Lumbee women found a new place and a new role for themselves. Krebs (1997), an American Indian, who studied 15 American Indian women breast cancer survivors living in an urban setting from 13 different tribes, proposed a theoretical model of breast cancer survival for American Indian women. In the model, the core category, recreating harmony, is achieved through four subcategories: (a) gaining strength, (b) managing emotions, (c) maintaining positivity, and (d) moving on.

In this study, three of the four subcategories in the model proposed by Krebs were found. Lumbee women discussed gaining strength from others and their faith. Lumbee women spoke of the importance of maintaining a positive attitude and their decisions to move on. However, while they did speak of emotions, they did not address managing emotions. Even in the retelling of their stories, they cried, cleared their throats at critical points, laughed nervously, and spoke with

trembling voices. All these emotions were included in the re-telling of their tremulous experiences of the diagnosis, the struggle to move through treatment and the joy of surviving.

The findings for this study have much in common with the findings of a second study of American Indian breast cancer survivors by Kiser-Larson (1999). The study populations of this study were similar to study population of Kiser-Larson in that both the time period between the diagnosis and interview ranged from less than 24 months to greater than 10 years. Kiser-Larson used Newmen's theoretical framework to study 10 American Indian women from seven different tribes to look for life patterns of interactions of cancer survivors with their environment. Kiser-Larson found that, like the Lumbee women, the women in her study showed 1) an initial response of "a life of disorder and chaos" (p. 102), accompanied by fear and disbelief, 2) grief of disfigurement and uncertainty, 3) the significance of family and friends for regaining stability, recovery and healing; 4) a renewed application for life and sense of gaining from the experiences, and 5) spiritual strengthening and a changed life during their cancer treatment.

Kiser-Larson found that connectedness through relationships was an identified previous life pattern that women used to understand the experience of breast cancer and acknowledged that the women expressed appreciation for the opportunity to tell their stories. Interestingly, she disclosed that women felt vulnerable and isolated with a sense of being different, a finding not found in this study of Lumbee women. Though Kiser-Larson's findings are congruent with Newman's theory and the unitary-transformative perspective that allows for the pattern of person-environment to unfold, she did not discuss finding the integrality of person and community, a central finding of this study.

Nursing studies of breast cancer survivors. The findings of this study are similar to findings of other nursing studies about surviving breast cancer. Unlike this study, most of the study populations in the other nursing studies are usually limited to women who were within 24 months of diagnosis and do not include American Indian women. Still, the first two phases, encountering breast cancer and moving on, were identified as were some of the same patterns used by women in other studies to survive.

In *Encountering Breast Cancer*, Lumbee women spoke of initial fear and an immediate feeling of disorientation and loss. Only feeling an immediate loss was in the nursing literature (Boehmke & Dickerson, 2006; Moch, 1990). Though fear was the most prevalent reaction for Lumbee women, it was not mentioned in the findings of the studies reviewed in the nursing literature. For Lumbee women, fear was of dying and of their responses to the difficulties that lay ahead. Moch (1990) and Boehmke and Dicherson (2006) reviewed findings of women's search for information by asking health care providers and also by independently researching breast cancer. Lumbee women told of getting information and choices of treatment from caregivers, family and community members, with only three mentioning any type of independent reading or searching.

In the phase *Moving On*, three of the five patterns were found in the nursing literature. In *Deciding to Move On*, 15 of the 16 Lumbee women told of their decision to fight breast cancer and to live. Only Boehmke and Dickerson (2006), using an interpretative methodology, report anything akin to this decision. *Dealing with Disfigurement and Suffering from Treatment* was reported in all the studies (Boehmke & Dickerson, 2005; Boehmke & Dickerson, 2006; Luker et al, 1996; Moch, 1990; Richer & Ezer 2002). Remaining *active*, especially those related to continuing their previous roles, were found by Boehmke and Dickerson (2005 and 2006), Luker et al, (1996), Moch (1990) and Richer and Ezer (2002). *Faith, the Bases for Moving Through and Not Claiming* did not occur in any of the reviewed studies.

None of nursing studies of non-American Indian populations report the reciprocity of the personal and communal worlds, but one student did have a similar finding. The primary focus of the reviewed nursing literature was the personal realities of the women studied, with one study reporting on social networks as a critical finding (McGrath et al., 1999). Women who lived in rural Queensland, Australia, operated within a strong, informal network of support. As with the study of Lumbee women who live primarily in rural North Carolina, the women in rural Australia used their social networks for support and information. However, they did not report a sense that these networks were integral to the women's sense of self.

Model of Nursing in American Indian Communities. Lumbee women breast cancer survivors told of reciprocity between their selves and their communal environment. They accepted and gave care, had reciprocity between their persons and communal environment, and relied heavily on traditional roles when being cared for and when caring for others as they progressed through various experiences until a new self was established. They relied on their own spiritual relationship and those of others to progress to a new self, then willingly shared their new spiritual self with others. Some of these themes are found in the Conceptual Framework of Nursing in the Native American Indian Culture (CFNNAC) developed by Lowe and Struthers (2001). Based on the premise that American Indians have a holistic worldview and experience life differently than the majority society (Struthers and Littlejohn, 1999), Lowe and Struthers studied American Indian nurses to determine a culturally appropriate nursing conceptual framework designed by and for American Indians. The CFNNAC includes seven dimensions: caring, traditions, respect, connection, holism, trust and spirituality.

Nursing Models. Lumbee women's discussions of an abyss, choice, interconnectedness with others, caring as presence and health as transformation are frequently appearing concepts in the nursing literature with a focus on topics other than breast cancer survival (Mitchell & Bunkers, 2003; Parse, 1992; Perkins, 2002; Reed, 2003; Watson, 2005). On hearing the words "breast cancer," some of the Lumbee women described a deep sense of distress, not being aware of their environment or time, or not knowing "how I got home." Such intense distress is referred to by Mitchell and Bunkers (2003) as an abyss. They conclude with a discussion of the abyss as an opportunity to reach self-actualization.

Various life events provide an opportunity for intense connectedness with self, others and the universe, but one has a choice as to engage or not. The consequences of choosing to follow these human connectedness experiences are the opportunities to "know self, bear witness with others, and to see the universe in new ways that are informed by truth (p. 21).

The Lumbee women told of their abyss and their decisions to move forward as well as their view of the experiences of breast cancer survival as having been for a purpose that allowed them to change or come into their new selves.

Perkins echoes the role of choice leading to the creative process of health as “conscious knowing.” Perkins describes an antecedent of conscious knowing as connectedness of being within themselves, others and the awareness of a presence higher than humans. Perkins notes that conscious knowing is fluid, flexible and offers the option to follow or not; it allows for pattern recognition and inspiration leading to creative processes. The Lumbee told of the role of prayer, faith in and connection to God and others as they made the decisions related to breast cancer treatment, their attitudes about breast cancer and their new lives. They tell their stories without divisions. They moved back and forth telling of their personal thoughts, decisions and interactions with community and God, as different truths within the same story. The Lumbee women describe the patterns they observed in others and themselves that they used to make choices and move on through the treatment of breast cancer.

In the phases breast cancer survival unveiled in this study, the women tell of progressing from their initial fears and vulnerability to a fulfillment of purpose and a new self and a new community. In themes of *Moving on Anew*, they report being content with life, having learned from the experiences of breast cancer and being a “better person.” Reed identifies the relationship between vulnerability and transcendence in her *Theory of Self-transcendence* (2003). She describes that a) increased vulnerability influences an increase in self-transcendence; b) increased self-transcendence is directly associated with a positive sense of well-being, while decreased self-transcendence is associated with depression and low self-concept, and c) personal and contextual factors moderate the two central relationships. Lumbee women reported fear which was not found in the nursing studies of other populations that reflected on the experiences as transforming. They stressed the need to remain positive and to connect with others and one’s god. Parse, in the *Theory of Human Becoming*, supports the view of humans as beings in a reciprocal relationship with their environment and health as becoming, the

accumulation of past and present experiences (1992). Finally, Lumbees tell of the importance of the spiritual self and community in all phases of surviving breast cancer. In “Moving on Anew”, their stories include finding a spiritual purpose in their experiences and caring for others through support and just “visiting” with them. Watson values the spiritual dimension and the presence of others in the caring experience (2005).

Summary of the discussions of the findings

While both the Lumbee and nursing literature is silent about the experiences of Lumbee women breast cancer survivors, both do provide different glimpses that support the probably of findings of this study. From this study, the Lumbee nurse researcher’s new understanding is that Lumbee women surviving breast cancer: a) has meaning in both their personal and communal worlds and that these are integral to each other, b) is a process that requires one and one’s community to move through different phases, c) the personal and communal worlds undergo the same three phases but have different patterns that are used to assist in survival, and d) survival is a transformative process for the woman and her community) . Previous nursing studies, including the nursing models of American Indian women breast cancer survivors developed by Krebs and Kiser-Lawson, supported the transformation process that provided meaning to the cancer experiences. A mixture of the phases was found in other nursing studies as well, but not all were found combined in any one study. Studies outside nursing and health echo the role of community for Lumbees. However, no other health study found the integrality of the personal and communal world. The findings of this study appear to be reflected in the CFNNAC.

Significance

From stories, nurses are tasked with interpretation and understanding of the human health-illness experience and then to use this interpretation to design nursing care. This study is the first purposed to understand the Lumbee health-illness experience and one of the few to provide insight into the experiences of American Indian women breast cancer survivors. The researcher in this study is a practicing Lumbee nurse, a unique position allowing a merging of Lumbee and nursing cultures and histories to lead to a better understanding the nursing needs of

this population. The findings of this study have significance for nursing education, nursing practice and nursing research.

Nursing practice.

The unique perspective will serve as a foundation for designing meaningful care to Lumbee people either as individuals or as community. In designing care, nurses should realize the reciprocity between the Lumbee person and their communal world. Though practicing nurses often involve family members in a patient's care, it is usually limited to teaching them about a condition or preparing for the patient's discharge. Practicing nurses will be surprised at the intensity of the relationship between a Lumbee woman and her community and might be distressed by the openness between the two as well as the role the community plays in decision-making and care. Laws protecting privacy are counterintuitive to the Lumbee culture, and special effort is required of nurses to blend the needs for community while practicing within the confidentiality required by law and professional ethics.

Secondly, nurses caring for Lumbee women should be prepared for the occurrence of the abyss and the process for progressing to transformation. Most nurses will not understand the fear and distress that may accompany hearing the diagnosis nor will they understand the role of spiritually and community in helping the women progress from the abyss to transformation. Often nurses refer patients to support groups or provide them with literature about breast cancer that gives the latest treatments and current survival rates. While the Lumbee woman requires her communal environment to exist, she does not participate in cancer support groups or find comfort in literature about surviving breast cancer. She needs direct involvement of her community and in her community to heal.

Finally, women who have survived breast cancer for a number of years still have needs to which nurses should attend. The problems associated with breast cancer, especially disfigurement and fear of reoccurrence, dwell with the women long past a given timeframe, possibly for the remainder of their lives. Nurses should care for these women as they adjust to their changing, aging bodies. The women in these stories described their new lives as active

participants with others. Nurses can work with them and their communities, encouraging and using this generative stage to benefit the Lumbee people.

Nursing education

This study about Lumbee women's experiences as breast cancer survivors raises questions for nursing education not necessarily related only to Lumbees but also to other marginalized or minority cultural groups. Nursing education must teach students to value understanding and recognize the differing responses to the health-illness experience. Most nursing curricula have some transcultural nursing content if not a transcultural nursing course. However, nurse educators must examine whether they promote understanding or simply provide a list of beliefs. To promote understanding while also learning differences in health-illness experiences, nursing educators should seek experimental learning opportunities for students which include listening to the stories of others and reflecting on what they've heard people say about themselves as individuals, how they define self, and how they pursue the nursing care they desire. Thus, listening would require more than just collecting information to complete a history form or a survey to determine one's learning style, but to listen for understanding. Such direction in nursing education will become increasingly important as populations change, not just with increased numbers of minority groups but an increase in the number of generations as well.

Nursing education should also ask, "What we are learning from our students whose backgrounds are outside the majority culture?" The ranks of nursing continue to be more homogenous than those for whom they serve. How are nurse educators listening to students and supporting them as they bring their cultural understanding into nursing? How are students being encouraged to blend their culture with nursing and share it with others?

Nursing research

This study of Lumbee women has significance for nursing research more than providing information about the Lumbee women. Nursing theories that define the human as open and in communion with their environment will find empirical confirmation of such in this study. From the stories of these Lumbee women, the openness and integrality of the person and the environment

in the meta-paradigm are revealed. But one must wonder if a different method, one that was not part of the women's culture, would have revealed this phenomenon? Should nursing research allow the question or the study population to determine the method of study used? Or, how can one blend these two to develop research studies?

As advocates for nursing care address nursing needs of all recipients, it is essential that the research include the community of concern. Community-based research as described by Averill (2005) allows the community to guide policies and programming, and research questions. Such research sees the community as the expert in their setting. Community-based action research includes and fosters a partnership with the community to help identify concerns, develop and implement interventions, and evaluate the effectiveness of the program/interventions, in turn, helping with resolution of misunderstandings among differing cultures and worldviews. Using more community-based research should strengthen nurses' commitment to respect those for whom we care (ANA, 2009).

Finally, this study demonstrates the value of studying survival. The Lumbee women provided a clear light to the path they walked in this process. As the population ages, survives life-threatening events and manages chronic diseases, nurses can learn from their stories and use this information to develop nursing interventions including the value of nursing.

Recommendation for further study

Based on the findings of this interpretative hermeneutic research study of what Lumbee women tell about their experiences of surviving breast cancer, suggestions for future study include:

1. In this research study the research question required that the women's be analyzed as a set, not as individual stories. By returning to these stories as individual accounts additional insight into nursing needs could be grasped. For example, the women reported getting information from others in the community and helping to plan mammography screenings in their communities. Nurses could use the information provided in this study to begin a dialogue with the community about specific nursing needs. The researcher's

interest is heightened by the results of a recent study. Friederichs-Fitzwater, studying urban American Indians in California, found that educational interventions designed by the community and conducted by American Indian women were more successful than other educational efforts (U.C.Davis, 2009). What nursing needs would Lumbee women identify?

2. The CFNNAC used a similar method to determine a nursing framework for working with American Indian populations from the perspective of nurses. This study data provides information about American Indians from listening to stories by Lumbee women. A third research questions arises from reflection on this finding of this study and the literature about the CFNNAC. How do the dimensions described in the CFNNAC compare and contrast with the worldview, phases and themes identified in this study?
3. In these stories women often told of loss of another family member to death, divorce and moving away. Krebs and Kiser-Larson also noted a need to study the role of previous losses on breast cancer survival. What is the role of loss on how one experiences breast cancer? Do people who discuss losses in their personal world experience more trauma or distress when confronted with breast cancer? Did women tell of communal loss such as historical trauma?

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APPENDIX A: TABLE OF PARTICIPANTS

Name	Education level	Age at diagnosis	Family history of breast cancer	Time since diagnosis	Type of treatment	Reoccurrence
Brenda	< than high school	60-70 years	Yes	5-10 years	Lumpectomy and radiation	No
Cathy	< than high school	Less than 40	No	>2 years	Lumpectomy and chemotherapy	No
Cora	< than high school	50-60 years	No	> than 10 years	Mastectomy	No
Dorcus	2-yr. college graduate	Less than 40	Yes	> than 10 years	Mastectomy and chemotherapy	No
Ethel	< than high school	50-60 years	No	> than 10 years	Mastectomy only	No
Fannie	< than high school	Less than 40	No	5-10 years	Mastectomy and chemotherapy	No
Jane	> 4-years of college	40-50	No	5-10 years	Mastectomy and chemotherapy	No
Joyce	Some college		Yes	5-10 years	Mastectomy and radiation	Yes
Laura	Some college	50-60	No	>2 years	Lumpectomy and radiation	No
Lucy	High school graduate	Less than 40	No	5-10 years	Mastectomy and chemotherapy	No
Maria	< than high school	50-60	No	> than 10 years	Mastectomy only	No
Martha	Some college	40-50	Yes	5-10 yeas	Mastectomy, chemotherapy and radiation	Yes
Mary	High school graduate	60-70	No	5-10 years	Lumpectomy and radiation	No
Millicent	College graduate		No	5-10 years	Mastectomy and chemotherapy	No
Nettie	< than high school	50-60	No	> than 10 years	Mastectomy and chemotherapy	No
Pauline	High school graduate	40-50	yes	< 2 years	Mastectomy and chemotherapy	No

APPENDIX B: ADDITIONAL QUOTES

Personal World

Encountering Breast Cancer

Disruption of self and disbelief

Dorcus: *I really, I really knew that I had breast cancer. I knew. I knew that I did. But then when the doctor said the word—what he said to me was—they did a biopsy and I went in to get the biopsy report, he says, “Well,” he says, “you’ve got a common thing.” That was the terminology he used. And it just hit me like a ton of bricks—“a common thing.” I knew it was common thing. I’d seen women every week, took care of women every week at the hospital that had it, had breast cancer, you know? But when it come home to ME, you know-- It was like when he said that, I didn’t hear it. I hear him talking, but I didn’t know what he was saying. I mean, it was like my ears just closed up, for it to be directed at me. But I really, I mean, I knew, like I say, I knew, but-- It’s kind of strange, when it comes home to you that, you know, this is-- And you see your life flash before you*

Ethel: *Right, mm-hmm. But I didn’t want to believe it. He was telling me I had cancer, and it was just going in one ear and out the other. And so, when we got home, after I had the biopsy and we got home, I told my husband, and he said, “I don’t believe you got cancer either.” Like I said, I just didn’t believe it. And he even took it out, when he did the surgery, he took it out and he showed it to my husband. And he had told him that it was cancer, but he didn’t tell me. But I knowed he had a funny look on his face. And so when I went back to him, he said, “I don’t know no other way to do but just tell you what it is. It’s cancer.” And I just passed out. I just fainted. I went out.*

Millicent: *And I became very despondent at that time, because, you know, when*

cancer's pronounced upon you, no one knows what it's like. No one can imagine or comprehend.

Pauline: *I don't know, it took me a while to get home because, you know, it messed up my mind so bad. And when I got here, my step-children was here, I believe all of them was here at that time. I broke down in the porch before I could get in the house, and I had to tell them all that I had—breast cancer—and they had to take my breast off.*

Mary: *I talked to my doctor, mostly. You know what to do. 'Cause none of my family had had breast cancer. None of them had had breast cancer yet, at that-- Well, there not any of them had breast cancer yet, so far. None of the girls—nor the boys. Oh, I have a brother that has prostate cancer.*

Dorcus: *But originally, when I felt the lump, it would move around. And then it became stationary, and I knew then—still in nursing school—that it was cancerous. But I wanted to finish nursing. So I held in there and finished the nursing program, and then three weeks afterwards I had my breast removed. Ah, yeah, sometimes I would have like a stabbing pain that would shoot through my breast like—I don't know what it would feel like for somebody to stick a knife in you, but that's kind of what I felt like a knife sticking in you probably felt like. That's the way that pain would shoot through my breast, like somebody took a knife, just went down on your breast and—*

Decision about Treatment

Laura: *[E]verybody is different. I had one of my, another, a friend of mine who had breast cancer, she had to have a mastectomy, and she would – I offered her my books, but she said she didn't want to read, she didn't want to know anything. She just took whatever the doctor said, she just took it, and didn't ask any questions. You see, I guess I'm a little bit different; I have a lot of questions. I want to know why I'm taking this, what's going to happen to me, what's the end –*

you know, what's the long-term? How is it going to affect my body? What is the quality of life I'm going to have? And that's the thing that I worried about, the quality of life that I was going to have after taking radiation.

Martha: *And he advised me that he had—large as it was, to remove the breast. So that was kind of hard at first.*

Nettie: *Thank God I didn't have to take the chemotherapy. I see people that did take it, that go through the sickness, and their hair coming out, maybe. And I'm just thanking God that I didn't have this to face. I mean, I can relate to people by going just through part of the situation. I mean, I count myself lucky that I just had to take medicine for five long years. But it breaks my heart, you know, to see somebody that's having to take this chemotherapy, and be so sick, and you know, different things happening to them. But most people that this is happening to, you'd be amazed at how they can talk with you.*

Mary: *So I told him to go ahead—he wanted to take my breast off, and I wouldn't let him. I says, "No—way." So he went and took that lump out, and he says it was as big as a golf ball. But it was big setting up there. You could feel it. But anyway, he said he didn't get it out, so he went in the second time.*

Moving Through

Deciding to move on with a positive attitude

Cathy: *The will to get better. Don't give up. If you give up, there's—I mean, you're not—if you give up, you're not going to get better. Fight, fight it, because you can overcome it.*

Dorcus: *See, I'm a very positive person. I'm not a negative person, I'm a very positive person. I look at things on the positive side. And I've always been a strong person, and I take on more than my share.*

Fannie: *I've come to look at it that, after so long, it just come to me it was going to be like that, and weren't nothing I could do. Just had to get on with life and be happy*

Martha: *Well, it was hard to take. But – I said, “Well, I’ll just take it, and see what I have to go do next.” I done radiation then. . Yeah, all those little things coming up. But I can get by those.*

Nettie: *But to me, I’ve like had to accept that this is something, like, you know, this is like losing a part of you that you know so well. It’s gone now and you have to accept it. You have to accept things that happens to you. If you don’t you never get over them. You want to get over it, and you want to get on. And that’s what I was wanting to do. Get over it and get on with my life.*

Faith: *The basis for moving through*

Brenda: *And then on the other hand, if you look at it being something that makes us get closer to the Lord--look at it that way, ‘cause He can help us over anything. Anything that happens, He can help us over it, help us get through it. And that makes you stronger. And then you () anything with Jesus’ help. And the next thing is getting your mind set on reading the Bible. That’s what helps you pull over this here, that’s what helps you pull over.*

Ethel: *I feel now like I couldn’t make it without the Lord, because He’s done so much for me. He’s done a lot for me. He’s really done more for me than I’ve done for Him. (Laughs) And I just, I love church, and love the Lord.*

Mary: *Well, it was between your faith and his faith. You’ve got to come to agreement, you and the person that’s a-praying for you, come to agreement that-- And you’ll be healed. If you’ll got that faith. And you’ll be healed. If you’ll got that faith. It says if you.*

Maria: *Yeah, I decided to get up and walk on the Lord.*

Pauline: *I—people said they was going to pray for me at church, and I think that helped a lot too, when I was going through this. So I said soon as I got better I was going back to church too. So I went to all the churches of the people that prayed for me, and then I went back to my home church. I thanked everybody for praying*

for me, because I think that's what made me stronger. I think it's good to have the Lord in your life. It makes you get along much better, I think, with the Lord in your life.

Remaining active

Maria *Yeah, Lord. I likes it now. I'd rather be out there in the yard now doing something or other. I love to work out in the yard with the flowers. I love that. Lord, yeah. I've been out there, hoeing around my flowers, ever since I could get out there. Lord, I loves it.*

Pauline *After it was over with, you know, what I went through, and tried to work too, when I did my chemo... After two months they decided to let me take those shots for--my red cells was low anyway. That would help build me up so I could work. And that really helped me a lot, so I could work and still go do my chemo. I'd try to do it on Fridays so I could recuperate on the weekends.*

Dealing with disfigurement

Cathy *Um, staying off my feet while I was taking the medicine, because I would be real sick. I would get nauseated. And walking around too much would make me dizzy, and if I fell and hit the spot where they had done the surgery it could bust open, because they didn't stitch it. They just put butterfly tape across it. And my breast was swollen real bad. I stayed in bed for a week. They didn't want me to get out of bed for a week. After that I started getting up and moving around. I couldn't eat very much. And when I did eat—I told you I did eat (laughs)—whenever I did eat, it wouldn't stay down long. I lost a lot of weight, but I've gained most of my weight back now.*

Jane *So when I went to Duke and found out that I was not a candidate for the lumpectomy, I was devastated, knowing I was going -- And that's when I made my final decision to go ahead and do it all at one time -- have it removed, and then have a breast, the reconstructive surgery, done at the same time. So when you*

wake up, it's like you just had surgery, you haven't lost anything... I lost all my hair except for a little bit of peach fuzz on my bald head. I guess that was probably the most devastating part of it. And I knew, my doctors had told me, "You'll lose your hair with the type of medicine we're giving." There are so many different medicines they use with chemo. I was thankful not to get sick, and not to have to throw up like years ago. There's all kind of meds they give you now, before they give you treatment.

Laura So you can tell I'm very--I worry about appearance. I worried about, you know, if I had to take chemo I knew I'd lose my hair. I knew I wouldn't be at work. (Laughs) And – You just have to wait and find out the diagnosis before you can go jump in, because, since I didn't have to go through a lot like a lot of people did, I was blessed, because I just had to go through the radiation. The radiation wasn't horrible. You know, it wasn't horrible. It's just a few minutes. And I was charred afterwards, but in a week's time I had been able to start back using vitamin E, and I got back alright.

Moving on anew

A transformed self.

Brenda And then on the other hand, if you look at it being something that makes us get closer to the Lord--look at it that way, 'cause He can help us over anything. Anything that happens, He can help us over it, help us get through it. And that makes you stronger. And then you () anything with Jesus' help.

Caring for self

Brenda After I had went through all of that, and I still didn't accept it, being one I didn't think I needed to mess with it anymore. But they kept on me 'til they got me started, so I've been taking a mammogram every year.

Ethel Mm-hmm, yeah, I had to do exercises. With my arm, I would have to take this arm and carry it over and touch my ear with it, because it was like—it was like, stiff-like,

you know. I didn't hardly have—couldn't hardly-- At first I couldn't come up. I just raised it up, and I kept doing it 'till I got it over here. Mm-hmm. And now I think they go and get therapy for that, now, which back then they didn't. But I weren't pointed to go get none. But now I go to the—the Lifestyle Center, and I take water aerobics. And that's fun, it's a lot of fun. I go three days a week. It's a lot of ladies there, and we have a lot of fun together. Yeah, I like it. Mm-hmm. I didn't know whether I would or not when I first went, but I really do like it. Yeah. And it helps me too.

Nettie *Get the mammogram once a year, and also have chest x-rays. They do both of these at the same time if you would like, or otherwise you can do one one time. But I usually go ahead and get the mammogram and get the chest x-ray. And they do it once a year. I've had it for the last seven year.*

Disfigurement -Still

Fannie *After I had my breast removed, that was the hardest thing, I guess, to look at.. . I've come to look at it that, after so long, it just come to me it was going to be like that, and weren't nothing I could do. Just had to get on with life and be happy.*

Cathy *Because I have the scar! (Laughs) And I have to watch—you know, if I wear a certain kind of shirt, my scar will show, and it looks bad. To me it looks bad ... I have hair now. (Laughs) And I'm healthier. After I started getting well--you know, I have never weighed over a hundred pound in my life--and after my surgery and everything and I got back to eating, I actually weigh now a hundred and twenty-seven pound. (Laughs)*

Cora *Well, now, there, one time, I thought, you know, before I got my – before I got well enough to get my thing, I thought people'd look at me. And it would bother me a little. But it don't bother me no more.*

Reoccurrence

Ethel *I guess it was probably when I said I didn't believe I had cancer. That was part of my faith. You know. And people praying. And I believe it, you know, I believe in*

healing, and I think the Lord had a lot to do with it as well, you know, through Him by the doctor. I think God works (?). I just believe it, and I don't think it'll ever come back there.

Communal Experience

Encountering breast cancer

Nettie *But my husband, I had to do my own breast exams, so lots of times I'd have him to help me. Lay on my back and have to help me. So he finds this – he finds this one little special place that he said, you know, it felt different. And so he said, "Maybe you should talk to your doctor and have this checked." ... – three days, my doctor was calling my husband, you know, telling him to bring me in, he needed to talk to me and the doctor tried to get him to tell me then, "Tell her while her parents is there." But he didn't. He, when my company left, he was like acting strange, but, you know, I was like, you know, not dwelling on it. So before we went to bed, he decided he would tell me. I says, "How come you didn't then tell me?" you know. I was like, he said, "Well, the doctor ain't told me too much. I didn't want you to get excited. But he do want to see you, and he do want me to come." And when he asked for the husband to come, I knew right then that something was going on. Or eitherwise, you know, he'd have just told me to come in. But he asked for my husband to come. (Sniffs, clears throat)*

Not of our people

Joyce *Well, when they first diagnosed Mamma, you know, it worried us to death, because the age Mamma was. Then when it was L, I thought we could not believe that she was so young. She won't but--she was thirty-three. I think she was thirty-three when she was diagnosed. And we thought our world had come to an end. We were all upset, but she was handling it okay. And she said, "The Lord will bring me through it." But when I got it, I told the doctor--he said it's hereditary--I said, "Well,*

nothing like this has every happened to our family, being hereditary.” () they have sugar (diabetes), my husband has sugar. But we handled it well.

Laura *But at that time we’d never heard of cancer. But like I said, at that time cancer had not come on the scene, say, fifty years ago, like it is today. It’s so rampant today, but fifty years ago it had not come on the scene,*

Nettie *Well, there was a lot came over here, you know, just supported me while I was going through the phase of this thing, you know. Lots of them was like I was, it was kind of new, because right around in our area, since I’ve had my surgery, since I’ve had mine, there’s been four or five people. But I only knew one person, you know, that was close related to me, that had had it. So there was lots of people it was new to them too. You know, like all my friends that was around, you know, was like, they hadn’t ever experienced it. And so they comforted the best they can with what little they know.*

Shared fear, shock and grief

Cathy: *They were scared. You know, first reaction, they were saying, “She’s going to die.” Or, “She’s going to lose her breast, and she’s so young.” At first I looked at it that way, but once I sit and thought about it, no, the Bible tells you God (has a purpose?).*

Ethel: *Hmm, (laughs), he was, he was excited. You know, it was just bothering him. He worried about me. It was a shock. It was really a shock to them.*

Fannie: *They were more like me, they were devastated, upset. But we – they were there, real supportive. I mean, my side of the family and my husband’s side. And he was real supportive. He was there for me.*

Laura: *Scared feelings. Frightened feelings. I’m sorry. (Crying).*

Maria: *Oh, it quite frightened them, but it didn’t frighten me a bit. They was scared that I’d have it all over me or something or another. Seemed like all of them was trying to*

help me or be good to me or something or other. But it didn't bother me. It didn't. I don't know, I've always been a person that nothing didn't bother me much. I didn't think of it.

Pauline: *They're afraid to be told that—they don't want to endure what you'd have to endure, such as chemo and radiation. And some of them don't want to be told, because they do not have insurance, and they feel that, by not having insurance, that they're not going to get the proper care that they would get. Because, you know, thinking of cancer, you think you're going to die. Some people would think that.*

Nothing to face alone

Jane: *And my husband and my sisters – I have three sisters – all went and stayed through the surgery, which was like, overnight, and maybe two days. My husband stayed the entire week, and one sister stayed all week with me too. They were back and forth. They had a hotel and they were back and forth, in and out, with me all the time. And then my mother-in-law took care of my daughters and everything at home.*

Joyce: *Well, he was at work, and I called him. And I was upset, and he said, "Well, J, don't worry about it." He said, "With the Lord's help we'll overcome." He's very strong, and he's a very big support. I told him.[son] He didn't quite understand. But he was seven, that was the year that he had to go to summer school. And I didn't know it was bothering him that bad, 'cause he was so young. And my daughter, she's my hero. She's always been there for me. She just stepped in and took my place when I'm down. [Telling of the day she had the biopsy and her son had to talk with her from school] "Son, I'm not going to leave you." I said, "Mamma is just going to have a little minor surgery, and I'll be home when you get home." And sure enough-- I said, "I'll be home shortly," 'cause he got home at twelve, and I said, "I'll be home shortly, so don't worry about Mamma." So, his teacher got back on there and she says, "I'm so glad you talked to him, 'cause he was so worried about you and so concerned about you." I said, "Well, I didn't tell him a lot because I didn't want him*

to worry, 'cause I didn't think he might not understand." but I believe--I'm a firm believer of this--I try not to keep anything from my children, 'cause my daughter was only twelve and she said, "Mamma, I'm your best friend," she says, "You're supposed to tell me everything that goes on." And I do, I tell them a lot. You know, people try to hide things from her. She said, "Mamma, don't hurt us like that. Don't try to keep anything from us. You tell us, 'cause we can't help you unless you tell us." Yeah. And I called Mamma, and Lord, Mamma like to have lost it. But I said, "Mamma, don't worry. I'm alright." I said--'cause I think she got four more days staying, I said, "Mamma, don't worry." I said, "I've got W and Ni at home," and I said, "There's A and G, S, and the rest of the family. Don't worry about me. Mamma, you have a good time." After that, I think when she come home now, this was the first place she came. She came to see me. But she just said, "Lord have mercy." It was my sister Lucy (in this study) had just finished chemo. Then that's when I was diagnosed with cancer. Oh, she broke down. She just cried. She said, "Lord, Joyce, I hope you don't have to go through what I had to." But we were there for one another.

Pauline: *And when I got here, my step-children was here, I believe all of them was here at that time. I broke down in the porch before I could get in the house, and I had to tell them all that I had—breast cancer—and they had to take my breast off. They was real comforting, though, when I told them.*

Deciding on treatment

Fannie: *So, my husband and I, we decided to go ahead and have the surgery. He told me after I'd had the surgery I would probably have to take chemo treatments, which I did.*

Knowing through communal suffering.

Cora: *[Speaking of a woman in her church] Well, she just told me, anything I needed, or if she could be of any help, to let her know and she'd be glad to help. I mean, I*

knew I had somebody out there I could reach to.

Lucy: *[So did you feel like you needed another kind of support group, then, had it been available?] Mm-mn, no. No. I had my family. I had my family, and my church family.*

Laura: *There were already two in my church, which was C B – she was a cancer survivor, she had, I think, had colon cancer – and J H had breast cancer. So they came to my rescue. And then I have four friends that I finished high school with, and we always have stayed real close. They came to my rescue. Plus many other friends, you know, who maybe – by working here I found a lot of people who had had breast cancer, and then say, “Well, can I have my sister call you and talk to you?” So I had a lot of people calling me, and saying, you know, “You can do it. I’ve done it.” ... Support groups. But I just did it once, because it, you hear some such sad, sad, sad – it’s just so disturbing, and I just cried all the way out, because I really – I had so much to be thankful for considering I didn’t have six months. I call that a death warrant. And this man was young. He was thirty-some years old, had a family. It was just devastating to hear that. But I did share it, you know, mine, with them, because you never know what you might say that might help someone.*

Mary: *Well, they would call me, and told me things to do, to try to help me. You know? I know one lady—I didn’t know, somebody must have told her, and she called me and give me a lot of good points, you know. But I’m the type of person, if something happens, it’s going to have to be like my sisters to know first, and anybody else, they’d get to hear it from them. It won’t be from me.*

The faith of others

Ethel: *I guess it was probably when I said I didn’t believe I had cancer. That was part of my faith. You know. And people praying. And I believe it, you know, I believe in healing, and I think the Lord had a lot to do with it as well, you know, through Him by the*

doctor. I think God works (?). I just believe it, and I don't think it'll ever come back there.

Millicent: I would have like twenty to thirty people coming to my home every day to pray for me. And what helped me survive, along with God, was the ministers, the Native American ministers. And the black people and white people came in and prayed for me. So I can't say just one race. I had more Native Americans, It's like Reverend Mike had me under one wing, and Reverend C. M. under the other wing. And Preacher Mike would call me constantly to go to Harper's Ferry Church, Elrod Church, Baker's Chapel. And then I had a husband to lean on. Now, lots of women—now, I'll tell you this—if I had been a single woman or a widow, I don't know what I would have done. I don't know what. I could not have driven to Duke. I would have cried all day long and night. And I did. And I'd always ask my husband to pray for me, and in twenty minutes my nerves would get better. I'd ask him to pray again. Maybe an hour, he would pray again. He has prayed twelve, fifteen times for me in one day!

Pauline: Oh yeah, everybody praying for me in the church, you know. And I don't know, the more I go to church now, the stronger I get. Yeah, and I go on Wednesday nights, on Bible studies, and I go to singings. I go to any singings that—even black churches have them, white churches too--I'll go to either one of them long as there's singing.

Depending on others

Fannie: Well, like I said, it – knocked us off at one point, but after we got through with it, I mean, they – my children were supportive too. I mean, we've come through it. They understood, you know, what was going on and everything.

Lucy: Well, I know of one girl – she was my best friend's little sister, and I had to babysit, I was always the mother of her, took care of her, go give her a bath – and she had her little boy came for his shots for school, and for some reason, they asked if anybody in their church going through chemo. And she remembered that I was

going, had went, through it, because my son was getting ready to go for his shots – my husband had to take him, because I couldn't, I was sick – and they had really never asked that, and they asked him, asked him that, and they had already got the shot ready, and they threw it away, because they said that if he would have cried and got the tears on me, I could have got polio from the shot.

Maria: *My knee-baby (second-youngest) girl. I stayed down there across the bridge there in that trailer with her, six weeks, and then I come home. And she did, she would come in before I went to the hospital, and check on me, see how I's a-doing.*

Martha: *Yeah, they help. Yeah, they help me out a lot. They notice, they know things that I can't do like I used to, and they're very supportive about that.*

Mary: *Well, they hope (help) a lot too. I'd—well, the first time after I did have my operation, one of my nieces had to go with me to drive me home. They didn't, they wouldn't let you drive yourself home. So you have to have somebody. You've got to have somebody to depend on, to help you, when you can't help yourself.*

Millicent: *But it does affect a whole family. It just didn't affect me. I think it affects the spouse more than the person that has the cancer. Because it affected my husband more than it did me, when I was told that I had cancer. If you notice, I say, "When I was told." (Laughs) It took a big toll on my husband. A bigger toll on my husband, I think. And then he had the responsibility, and had to care for me, and all the transporting back and forth, and seeing me during the night and day. It was a twenty-four-hour. He retired, and he wouldn't walk to the mailbox and leave me if someone wasn't in there with me. And that was amazing.*

Concern for others

Lucy: *Mm-hmm. Well, my mother had it about a year before I did, and I'd go and help her out, and try to do things for her. And then me and my sister (Joyce in this study) was going through it basically at the same time, and she was taking care of me, because*

my last treatment, she had just had her surgery, and she had a FIT until I came here and stayed. So when I had a treatment, I slept for three days. But she took care of Josh for me. And she'd just had surgery herself. But she didn't rest until I came, so I finally gave in and came here and stayed with her.

Pauline: *I had a neighbor too, over here, I'll never forget. She would cook for me and my husband, and my son, because nobody wasn't here but me and my son and my husband. And you know, men don't do much cooking. (Laughs) She'd bring a lot of dishes over, and I had my sister would come and help me clean up, and help cook too. She'd cook supper too for me, help me out around the house. I really had a lot of support. From work too.*

Cathy: *Yes. My nieces and nephews is what kept me from sitting in a corner withering away, thinking about it all day. Most important factors of staying well. (Pause) Oh, gosh. That's a hard question. (Laughs)*

Moving on anew

Communal activities

Mary: *Recognition would mean that you'll know what tribe you're from, to get that down in writing where we people can be more so that, you know, have that's coming up...But we had to have all of that, and buy all of that. And as being recognized as a Indian, that they can have more opportunities. They have more opportunities now than they did back when I was coming up in school, whole lot more, as a Indian. Because my sister that lives in Michigan, she made sure that all of her children and grandchildren had Indian cards. They could go to school up there free, get free recognition as—what is it you call it, getting the help of going to school. Scholarships, that's good for that. So we need to, for our younger generation to realize that school is a very important thing in their life, that they need to get all they can now. If they don't, they'll nothing else around here to do. They better go to school and get them a education. other opportunities, and have*

opportunities like any other race. Yeah, for the children

Contributing to communal knowledge

Dorcus: *They're getting more fearful. Everybody's becoming more aware. You know, like, "I better go to the doctor more often." "I better—" And I influence my family or anybody I know, "Pressure the doctor to order—" My brother just had his kidney taken out last June, two weeks before he turned forty-nine years of age. He was forty-eight. The cancer found in his kidney was by accident, because he was having constipation, and I pressed him into talking his doctor into getting an x-ray done of his colon, because I had had colon cancer.*

Joyce: *We were close-knit anyway, but it has drawn us closer. We have more to talk about and to share with other women. If a question comes up and they don't know what to do, we just tell them how we feel, or how God has brought us through it. Yes, and I think with that they were going through. They knowed that I had already been through the process of having breast cancer and they wanted to know my reactions, but most of all my roots came from the Lord. If a question comes up and they don't know what to do, we just tell them how we feel, or how God has brought us through it. [I talk] One on one. Not in groups.*

Millicent: *And I have gone from church to church and I have given my testimony, I have given it over TV stations as well. I've been interviewed by the Robesonian, the Fayetteville Times, other papers, the Carolina Indian Voice. I've been to pretty much one-fourth of the churches in Robeson County... I don't go to support groups. I have enough to listen to here, so I don't go out to hear other people tell me about cancer, their problems. I want to be telling someone that had cancer that's not in a support group my testimony, instead of joining their support groups. I feel that we need to go out into the fields as individuals and work with people that have cancer. Anything that's pertaining to cancer, I think we need to contact local agencies, like this agency, LRDA, the Tribal Council, and leave leaflets there, and*

make sure we put the word on there, "Free, free, free. Save your life." I think we need to do more advertising of that, if we can get anything that's free other than with the triglycerides and the high cholesterol, and for the sugar.

Communal caring

Ethel: *I've cleaned their house, and I've been over there and cooked for my sister, and I've run errands (errands) for her, done stuff like that.*

Fannie: *I can get out and witness to people. Be a better Christian. Better mother, wife. Do what I can to help another person.*

Maria: *Tend to people. They call me and I go to their house and tend to their parents, or ever who it would be sick.*



University and Medical Center Institutional Review Board
East Carolina University

Ed Warren Life Sciences Building • 600 Moye Boulevard • LSB 104 • Greenville, NC 27834

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Chair and Director of Biomedical IRB: L. Wiley Nifong, MD

Chair and Director of Behavioral and Social Science IRB: Susan L. McCammon, PhD

TO: Cherry Beasley, 206 East 17th Street, Lumberton, NC 28358
FROM: UMCIRB *kn*
DATE: February 23, 2009
RE: Human Research Activities Determined to Meet Exempt Criteria
TITLE: "Breast Cancer Survivors' Stories: Understanding the Experience"

UMCIRB #09-0174

This research study has undergone IRB review on 2.14.09. It is the determination of the IRB Chairperson (or designee) that these activities meet the criteria set forth in the federal regulations for exemption from 45 CFR 46 Subpart A. These human research activities meet the criteria for an exempt status because it is a research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects. *NOTE: 1) This information must be existing on the date this IRB application is submitted. 2) The data collection tool may not have an identifier or code that links data to the source of the information.*

The Chairperson (or designee) deemed this **unfunded study no more than minimal risk**. This research study does not require any additional interaction with the UMCIRB unless there are proposed changes to this study. Any changes must be submitted to the UMCIRB for review prior to implementation to allow determination that proposed changes do not impact the activities eligibility for exempt status. Should it found that a proposed change does require more substantive review, you will be notified in writing within five business days.

The following items were reviewed in determination exempt certification:

- Internal Processing Form—Exempt Application (dated 2.2.09)

It was furthermore determined that the reviewer does not have a potential for conflict of interest on this study.

The UMCIRB applies 45 CFR 46, Subparts A-D, to all research reviewed by the UMCIRB regardless of the funding source. 21 CFR 50 and 21 CFR 56 are applied to all research studies that fall under the purview of Food and Drug Administration regulations. The UMCIRB follows applicable International Conference on Harmonisation Good Clinical Practice guidelines.



THE UNIVERSITY OF NORTH CAROLINA
AT
CHAPEL HILL

Committee on the Protection
of the Rights of Human Subjects
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TO: Bonnie C. Yankaskas, Ph.D.
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CAROLINA CAMPUS

FROM: The Committee on the Protection of the Rights
of Human Subjects

DATE: February 12 2002

SUBJECT: Research Application Review

STUDY: IRB# 00-RAD-104-ORC Title: The Native American Breast Cancer
Registry (NABCR)

This research proposal has been considered by the Committee and
it has been approved until February 12 2003.

- (1) Review Type: Full Committee
- (2) This Committee complies with the requirements found in Part 56 of the 21 Code of Federal Regulations and Part 46 of the 45 Code of Federal Regulations. The assurance of compliance with DHHS regulations is on file in the Committee office for your perusal. Assurance Number:M-1390; IRB Number: 01.
- (3) Re-review of this proposal is necessary before:
 - (a) making any significant alterations or additions to the proposal, except when necessary to eliminate apparent immediate hazards to the subject, or
 - (b) continuing beyond the approval date.
- (4) It is required that all signed consent forms be retained on file.
- (5) Approved consent form(s) enclosed.

Stephen A. Bernard, M.D.
Chairman of the Committees

FIGURE 1 MODEL OF FINDINGS

